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AUTHOR Ownby, Lisa L.; Hooke, Amanda C.; Moore, Dee Wylie; Garland, Corinne W.; Frank, Adrienne

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ABSTRACT

Four manuals on implementing the Partners Respite Model, which provides respite care for children with disabilities or chronic illnesses, comprise this document. The Community Planning Manual offers a step-by-step guide to replication of the Partners Respite Model and is divided into sections on developing the Partners program, implementing the Partners program, measuring program success, and offering resources. The Trainer's Workshop Manual is intended to be used for a 6-hour group training in implementing the model's 5 steps: (1) recruit families and caregivers; (2) conduct partners workshop; (3) help families choose caregivers; (4) guide families as they train their own caregivers; and (5) provide continuing support. The Family Manual guides families in choosing and training their own respite caregivers by using their children's daily routines to develop training plans. It also provides worksheets, resources, and forms. Finally, the Caregiver Manual offers basic information on caring for young children with disabilities and supporting families. It includes information about respite, communication, building partnerships, disabilities awareness, child development, children with special needs, and personalized training with families. (DB)

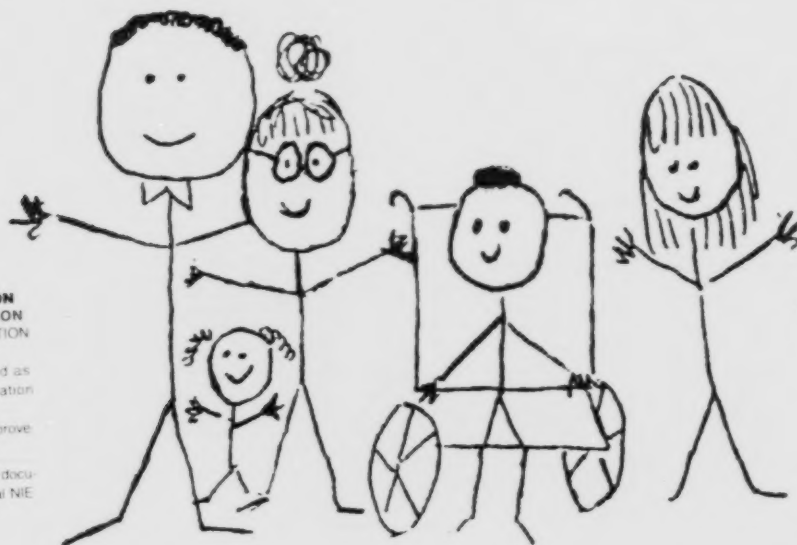
Partners *Plus*

Families and Caregivers
in Partnerships

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A Family-Centered Guide to Respite Care
Child Development Resources

Partners *Plus*

Families and Caregivers
in Partnerships:
A Family-Centered
Guide to Respite Care

By

Lisa L. Ownby, M.S.W.

Amanda C. Hooke, M.S.W.

Dee Wylie Moore, B.S.

Corinne W. Garland, M.Ed.



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Acknowledgments

The authors would like to thank Jayne Naughton for her technical assistance; Amy Watson for editorial assistance; families and caregivers who wrote the perspectives stories in section four of the Family and Caregiver Manuals; and our community advisory committee for multiple tasks throughout the development of training materials. Their suggestions and comments provided a significant contribution to the quality of this manual.

Amy Consiglio, of CM Consulting, designed and produced this manual.

A Word About Funding

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Funding to revise the Partners Plus manuals to help families use existing community programs as respite for their school-age children with mental retardation came from the Joseph P. Kennedy, Jr. Foundation. Revisions to the manuals include practical "how to" information for personnel working with children in before and after school programs, recreational, camp, and other community programs.

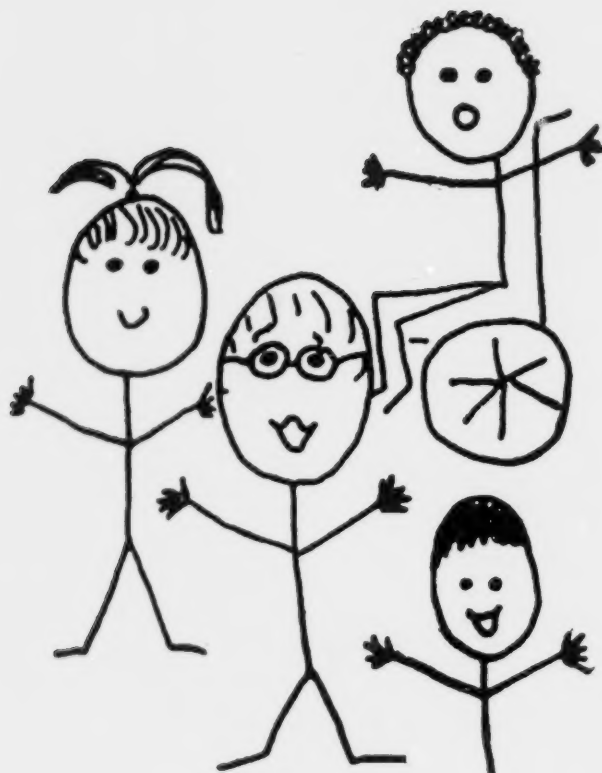
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Contents

- Community Manual
- Trainer's Workshop Manual
- Family Manual
- Caregiver Manual





Partners Plus

Foreward

Using this Guide

Format of this Guide

The **Partners Plus Guide** is a comprehensive resource that includes practical easy-to-use information to help communities establish a family-centered respite program. The **Guide** contains four individual manuals developed by Partners Plus, a program of Child Development Resources (CDR). Partners staff designed each manual for specific audiences. Partners designed the **Community Manual** to help community planning groups develop a respite program. The **Trainer's Workshop Manual** gives trainers the information they need to conduct workshops for families and caregivers. We designed the **Family Manual** and **Caregiver Manual** to meet the training needs of families and caregivers as they work together in respite partnerships.

Communities, families, caregivers, and trainers will find each manual useful as an independent resource or as a complete package for carrying out a community respite program. CDR Partners staff offer support and technical assistance to communities interested in replicating the Partners respite program. Please contact CDR to learn how we can help you establish a respite program in your community.

Child Development Resources

Phone: 747-220-1168

Fax: 757-253-1779

E-Mail: ppcdr@tni.net

Mail: 1490 Government Road
Williamsburg, VA 23185



Using this Guide

The Community Planning Manual

The **Community Planning Manual**, the first part of this **Guide**, describes the process for successful replication of the Partners model of family-centered respite care. Partners Plus and several community planning groups in Virginia used this manual as a resource while working toward replication of the Partners model. Coordinating leadership in an initial community planning group is the beginning process of replication that leads to conducting the Partners' workshop for families and caregivers. Continual support to families and caregivers follows a workshop as families and their caregivers develop long-term respite partnerships. In following the replication process, community leaders can work collaboratively with respite stakeholders to develop a respite care program. Partners divided the **Community Planning Manual** is divided into four sections:

- Developing your Partners program
- Implementing you Partners program
- Measuring your success
- Offering resources

When community planning groups are working together toward establishing their own Partners program they can easily pull the **Community Planning Manual** section out of the **Guide** to make copies of pages appropriate to group members' tasks.



Using this Guide

The Trainer's Workshop Manual

Staff of the Partners program designed the **Trainer's Workshop Manual** to help Partners trainers in planning and conducting the six-hour workshop for families and caregivers. Pages of the manual have holes to fit a three-ring binder so that trainers can add or remove contents to fit their presentation style. Some sections of the **Trainer's Workshop Manual** include the use of overhead projector transparencies. We provide master copies for making these transparencies at the end of each corresponding section. Partners trainers may choose to add some or all of the other **Guide** components to their personal **Trainer's Workshop Manual**.

The Family Manual

Staff of the Partners program designed the **Family Manual** for families to use in choosing and training their own respite caregivers. Communities may make additional copies for families or order them directly from CDR. At the beginning of a Partners workshop, trainers give each family a manual. During the workshop families learn to use the manual as a resource for finding and training their own caregivers. This manual guides families in using their children's daily routines to develop personalized training plans for respite caregivers. It includes information about respite, communication, building partnerships, selecting caregivers, and developing personalized training. The **Family Manual** contains worksheets, resources, and forms that can be duplicated for future use.

Using this Guide

The Caregiver Manual

Staff of the Partners program designed the **Caregiver Manual** to give caregivers basic information about caring for young children with disabilities and supporting families. Again, communities may reprint the whole manual or purchase them from CDR. At Partners workshops, trainers give caregivers a manual to use during the workshop that they can take with them afterwards for use as a resource when partnering with a family. This manual includes information about respite, communication, building partnerships, disabilities awareness, child development, children with special needs, and personalized caregiver training.



Notes on this Section



Partners *Plus*

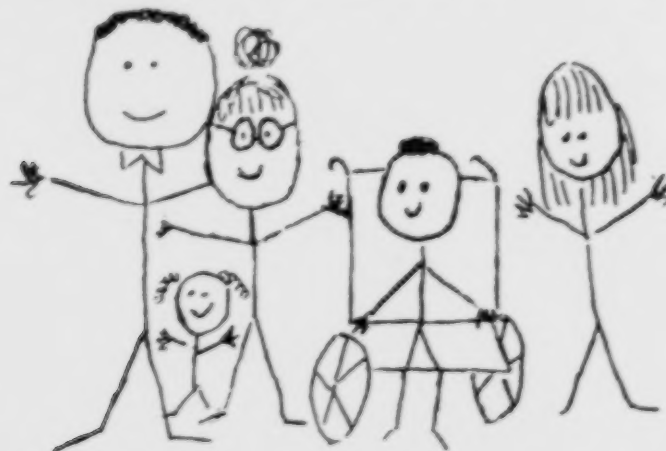
Families and Caregivers
in Partnerships:
Trainer's Workshop Manual



A Guide to Conducting Partners Plus Workshops
Child Development Resources

Partners *Plus*

Trainer's Workshop Manual



Families and Caregivers in Partnerships
Child Development Resources

Partners *Plus*

Trainer's Workshop Manual

Developed By

Amanda C. Hooke, M.S.W.

Lisa L. Ownby, M.S.W.

Dee Wylie Moore, B.S.

Corinne W. Garland, M.Ed.

Adrienne Frank, O.T.R.

The Trainer's Workshop Manual is part of a series of resources in the Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care. The rest of the series includes the Partners Plus Community Planning, Family, and Caregiver Manuals, created by Child Development Resources.



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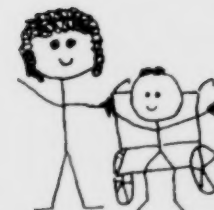
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Trainer's Workshop Manual

introduction

The Partners Model of Respite Care...

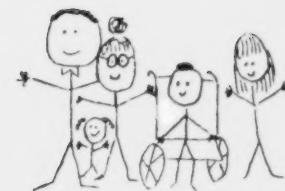
Helps families of children with special needs find and train their own respite caregivers.

Through training and support, families and caregivers build long-lasting, successful respite relationships.

Introduction

Like all families, families of children with special needs want and need time away from the demands of parenting. *Respite—or temporary child care for children with disabilities or chronic illness*—gives families time to enjoy an evening out by themselves, with other family members, or with friends. However, for these families, finding respite care is not as simple as calling a neighborhood babysitter. These families need caregivers who understand their children's special needs.

When the staff at Child Development Resources (CDR) spoke with families about what they wanted in a respite program, the message was clear. Families wanted to choose and train their own



respite caregivers. They wanted affordable care that was as simple to schedule as calling the neighborhood babysitter. And, families wanted caregivers who were trained to provide care.

In response to families and with support from the Virginia Institute for Developmental Disabilities (VIDD), a University Affiliated Program at Virginia Commonwealth University in Richmond, Virginia, CDR developed a pilot project that was low-cost, family-directed respite care called PARTners: Parents As Respite Trainers.

CDR was awarded, in 1994, a three-year grant from the U.S. Department of Education, Office of Special Education Programs (OSEP), Early Education Program for Children with Disabilities (EEPCD), to build on the pilot and to develop a model of respite that could be replicated in other communities. The project, **Partners Plus: Families and Caregivers in Partnerships**, provides a model for families to use in finding and training respite caregivers. This model encourages families to use available, **natural** family and **community** supports to meet their respite needs.

About the Partners Model

Within this model, Partners broadly defines the terms *respite* and *caregiver*. For example, respite can take place in a family's home, a caregiver's home, or in before and after school, recreation, camp, or other children's program. A caregiver can be any individual who *provides respite care* to a child with special needs or *includes* a child with special needs within an existing community program.

Partners Plus provided training to more than 200 families and caregivers in a five-city, three-county area of eastern Virginia. Partners usually conducted the six hour Partners Plus workshop for families and caregivers in one day. Sometimes when it was more convenient for a group, Partners conducted the workshop in two parts on separate days. This flexibility ensured that Partners adapted training to fit the schedules of families and caregivers who are generally most receptive to training during nontraditional hours such as evenings and Saturdays. Families attending the workshop learned to provide their own caregivers with personalized training based on their children's daily routines. Families either came to training with their own caregivers, met caregivers through the workshop, or through other project activities.

The Partners Project resulted in the development of four manuals designed to help communities, trainers, families, and caregivers use the Partners model. The **Trainer's Workshop Manual** is one of four in a series of manuals that Partners has conveniently packaged together in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**. Besides the set of manuals contained in the guide, you can purchase the **Family and Caregiver Manuals** separately from the Partners Plus program through CDR.

Child Development Resources
Post Office Box 280
Norge, VA 23127-0280
Phone (757) 566-3300
Fax (757) 566-8977
Email ppcdr@tni.net

Partners Model: 5 Steps

The Partners Model: A New Model of Respite Care

Partners programs provide group training and continuing support to families and potential caregivers. The Partners model contains five steps:

The Five Steps of the Partners Model

1. *Recruit Families and Caregivers*
2. *Conduct Partners Workshop*
3. *Help Families Choose Caregivers*
4. *Guide Families as they Train their Own Caregivers*
5. *Provide Continuing Support*

Step 1: Recruit Families

First, programs **recruit** families and potential caregivers to participate in Partners. Community awareness activities invite potential participants to a Partners workshop. Information about the workshop and the Partners program is distributed through parent groups, newspapers, radio, flyers, word of mouth, etc.

Step 2: Conduct Partners Workshop

Next, programs **conduct the Partners workshop**. During the six-hour workshop, families learn how to find, screen, and interview caregivers for their children. In addition, they learn to structure training for their own caregivers based on the specific needs and daily routines of their individual children. Caregivers learn basic information about caring for children with special needs. During the workshop, caregivers are preparing to be active in their work with families, reflecting on their motivations for becoming respite caregivers and identifying their own learning needs for personalized training. Partners **Family and Caregiver Manuals**

Partners Model: 5 Steps

provide participants with useful resources to actively engage in during the workshop and to use as resources as they move through the next steps of the model.

Step 3: Families Choose Caregivers

After the workshop, Partners programs provide continuing support as *families choose caregivers*. Families frequently identify respite caregivers within their own circles of natural support. If families are unable to identify their own caregivers, Partners will assist by providing social and educational events that will help families and caregivers meet. During interviews, families and caregivers negotiate how respite occurs. Respite may be in-home or out-of-home and reimbursement for care can be flexible. Care may be provided for a fee, voluntarily, or in exchange for another service, such as yard work.

Step 4: Families Train Caregivers

Once families and caregivers decide to work together, *families train their own caregivers*. This "personalized training," discussed

during the workshop, is organized by families with help from Partners staff if needed. Families decide what routines caregivers need to learn and work with caregivers to determine how training will occur, thus forming true partnerships necessary for successful respite.

Step 5: Provide Continuing Support

As families and caregivers work together to develop a personalized respite training, the community Partners program *offers continuing support*, information and guidance. The Partners program is available to support families and caregivers in various ways as they begin their respite relationship. Partners staff members respond to requests for help and support from both families and caregivers. For example, Partners may help families and caregivers with screening, interviewing, developing personalized training plans, and providing educational opportunities.

Partners Replication Process

Partners Plus Replication Process

The Partners Plus Community Planning Manual, contained in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**, helps communities use the Partners model of respite care. Each community interested in model replication develops a plan for collaboration among agencies, organizations, and individuals in order to implement the model. Community resources and supports are needed to sustain the model, to create a home for the program, and to ensure continuation.

The community replication process includes four major steps:

1. *Identifying the site for replication*
2. *Planning for replication*
3. *Implementing the model*
4. *Evaluating the model*

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The Partners Plus Community Planning Manual is a step-by-step guide for the replication process outlined in the flowchart on page xii.

Your community will be a good candidate for replication if you have the following:

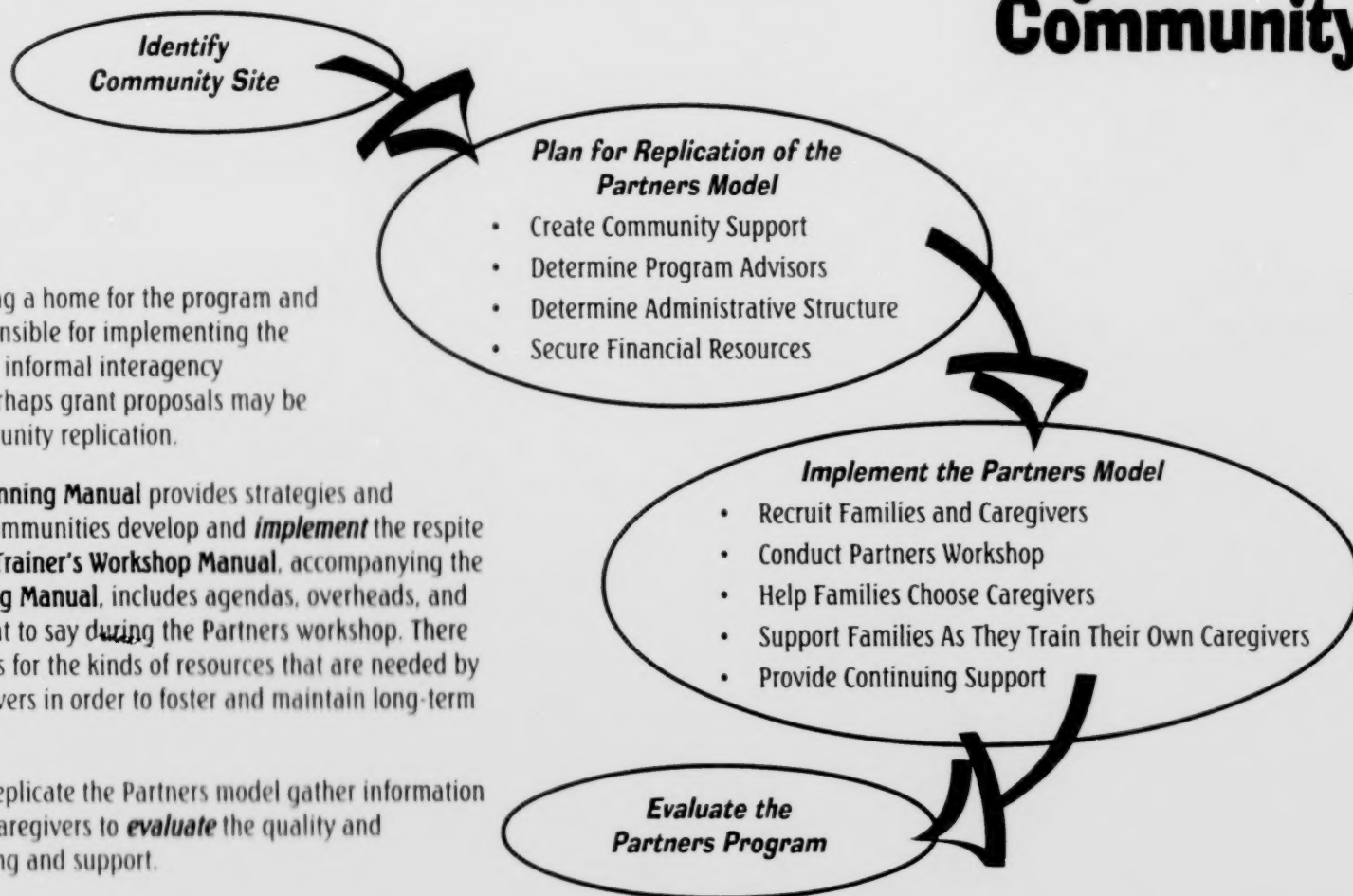
- support from agencies that provide, or are involved with, respite services
- knowledge of current respite funding to support families without financial resources
- support and commitment from local early intervention programs, mental health or mental retardation programs, and/or family support programs

Each community needs to develop a **plan for replication**. Awareness activities aimed at a broad array of agencies, organizations, and individuals help strengthen community support. The creation of an advisory committee brings expertise and resources that will ensure a quality program. The replication

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Partners Community Implementation Process

Partners in your Community



plan includes finding a home for the program and securing staff responsible for implementing the program. Formal or informal interagency agreements and perhaps grant proposals may be necessary for community replication.

The **Community Planning Manual** provides strategies and materials to help communities develop and **implement** the respite care program. The **Trainer's Workshop Manual**, accompanying the **Community Planning Manual**, includes agendas, overheads, and suggestions for what to say during the Partners workshop. There are also suggestions for the kinds of resources that are needed by families and caregivers in order to foster and maintain long-term relationships.

Communities that replicate the Partners model gather information from families and caregivers to **evaluate** the quality and usefulness of training and support.

Partners Plus Manuals

Partners Plus Manuals

There are four manuals in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care** that support the Partners Plus replication process:

1. The **Family Manual**
2. The **Caregiver Manual**
3. The **Community Planning Manual**, and
4. The **Trainer's Workshop Manual**.

The **Family** and **Caregiver Manuals** are used in the Partners workshop for families and caregivers. These manuals include resources that families and caregivers can continue to use as they develop partnerships for respite care for children with special needs. The **Community Planning Manual** helps communities develop a community-based, family-centered respite system. The **Trainer's Workshop Manual** contains overheads, forms, and "helpful hints" for conducting Partners workshops.

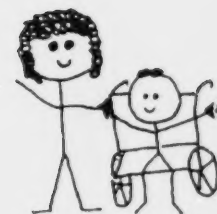
The **Family Manual** is easy to follow and guides families in choosing and training their own respite caregivers. Families use

their children's daily routines to develop training plans for caregivers. The manual includes information about respite, communication, building partnerships, selecting caregivers, and developing personalized training. There are worksheets, resources, and forms that can be duplicated for future use.

The **Caregiver Manual** provides caregivers with basic information on caring for young children with disabilities and supporting families. This manual includes information about respite, communication, building partnerships, disabilities awareness, child development, children with special needs, and personalized training with families.

The **Community Planning Manual** provides communities with a step-by-step guide to replication of the Partners model. By following each step, communities and families can work together to develop respite care programs. The manual contains forms and materials to assist with replication of the model.

The **Trainer's Workshop Manual**, used in conjunction with the **Community Planning Manual**, helps community trainers to conduct the six-hour Partners workshop for families and caregivers.



About the Partners Workshop

The six-hour Partners workshop helps families and caregivers gain knowledge and skills to build respite partnerships. The workshop can take place in one day-long session or two half-day sessions. Flexibility in scheduling workshops makes it easier for families and caregivers to attend the workshop on Saturdays or evenings.

In the workshop, families and caregivers participate in lectures, discussion and practice activities designed to meet the needs of adult learners. Activities and materials engage and inform participants in ways that support different styles of learning.

Partners divide the workshop into sections. Following this page is a flow chart to help trainers recognize how Partners organized information in this manual. To begin the workshop for participants, the trainer shares information from the Welcome to the Partners Workshop section. Families and caregivers stay together through the first few sections. Later, they split into family and caregiver groups for "Break-Out Sessions" designed to meet their different needs. Finally, families and caregivers reunite for a practice activity employing the skills developed through the workshop.



Flow Chart to the Trainer's Workshop Manual

Introduction

The first section of the Trainer's Workshop, Family, and Caregiver Manuals have the same Introduction.

How To Use the Trainer's Workshop Manual

The second section of the Trainer's Workshop Manual tells the trainer how to use the manual.

Welcome to the Partners Workshop

Workshop information for all participants begins in the Trainer's Workshop Manual at this section.

Sections 1-4: Participants Work Together

All workshop participants work together during sections 1, 2, 3, and 4, where the information is the same for both families and caregivers:

Section 1: About Respite

Section 2: Building Partnerships: Communication

Section 3: Building Partnerships: Families and Caregivers Working Together

Section 4: All Kids Like Cookies Activity

Sections 5-10: Participants Work Separately

After completing section 4, the group splits into families and caregivers, each working with a trainer on topics that are different:

Family Break-Out Session

Section 5-F: Finding Respite Caregivers

Section 6-F: Interviewing Caregivers

Section 7-F: Developing a Personalized Training Plan

Resources

Forms for Sharing Information

Caregiver Break-Out Session

Section 5-C: Disabilities Awareness

Section 6-C: Understanding Child Development

Section 7-C: Children with Special Needs

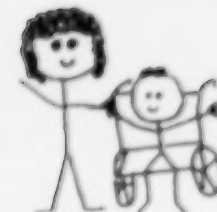
Section 8-C: Becoming a Caregiver

Resources

Forms for Sharing Information

Final Activity: Participants Work Together

After completing their sections, the two groups return for the Final Activity, involving daily routines to help develop a personalized training plan.



Partners Workshop Objectives

As a result of this workshop, families and caregivers will:

- Be able to define respite care and identify the benefits to families, children and caregivers,
- Know how families drive family-centered services, and what rights and responsibilities they have as participants in family-centered systems,
- Understand the Partners model of respite care,
- Know the importance of clear and open communication in a respite relationship,
- Know the variety of ways that people send and receive messages,
- Be able to recognize and mend communication breakdowns,
- Practice communication skills,
- Have firsthand experience of some of the challenges faced by children with special needs,
- Be able to identify the ways in which children with special needs adapt to their environments, and
- Practice developing a personalized training plan using a child's daily routines.

As a result of this workshop, families will:

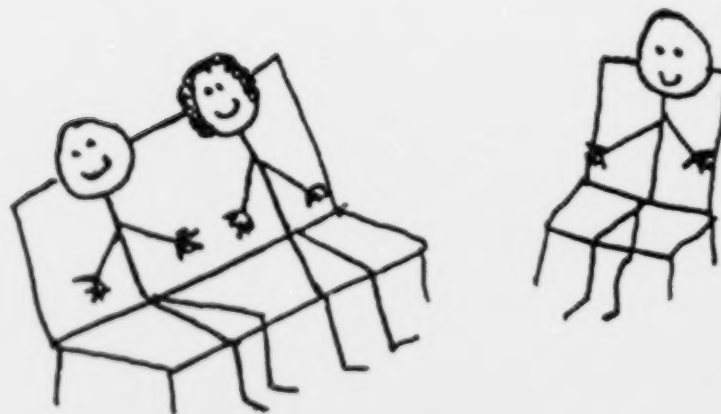
- Become more aware of caregivers' perspectives on caring for children with special needs,
- Understand why many caregivers experience "burn out" and stop providing respite care,
- Know strategies to prevent caregiver burn out,
- List qualities/criteria for selecting caregivers,
- Know other strategies for finding respite caregivers,
- Be able to identify potential caregivers in their natural support networks,
- Know what questions to ask caregivers in interviews,
- Understand different options for conducting interviews,
- Know other strategies for gathering information about caregivers,
- Understand the four-step process for teaching daily routines to caregivers,
- Know some principles for teaching adults, and
- Understand the importance of sharing emergency procedures and household rules with caregivers.

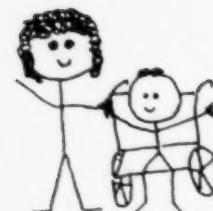
Partners Workshop Objectives

As a result of this workshop, caregivers will:

- Become more aware of the perspectives of families with children with special needs,
- Recognize families' need for respite and the value of the service that respite caregivers provide,
- Understand the importance of learning about a family's experience from that family,
- Understand common terms, services and issues related to children with special needs,
- Understand the basics of child development,
- Be aware of the importance of play and enriching environments for child development,
- Be aware of potential hazards in an environment and appropriate safety precautions,
- Be aware of the basic developmental and medical effects of common special needs on children,

- Be aware of what they may be asked to do when caring for children with common special needs,
- Know how to match with families for respite, and
- Understand how caregivers can contribute to personalized training.





Use of the Trainer's Workshop Manual

The **Trainer's Workshop Manual** gives trainers information on respite and helping families and caregivers develop skills to build strong respite partnerships. Experienced trainers enhance the workshop, however, Partners designed the manuals to help even inexperienced trainers to conduct successful workshops. It is especially beneficial when trainers can bring their personal or professional perspectives in disabilities to the workshop. While comfort and skills in teaching adults are also helpful, the **Trainer's Workshop Manual** helps trainers understand how to facilitate training and make it effective for participants with different learning styles.

Partners divides the workshop into Sections. The **Trainer's Workshop Manual** outlines training activities and includes overheads and supplemental materials for use in the workshop. Each Section begins with a list of the learning objectives, time and materials needed, and specific instructions that apply to the section content. Workshop notes to the trainer are on the left of each page. On the right of each page is a list of overheads or materials needed. In the center of each page in a bold font are suggested ways to present essential information using specific words or phrases. However,

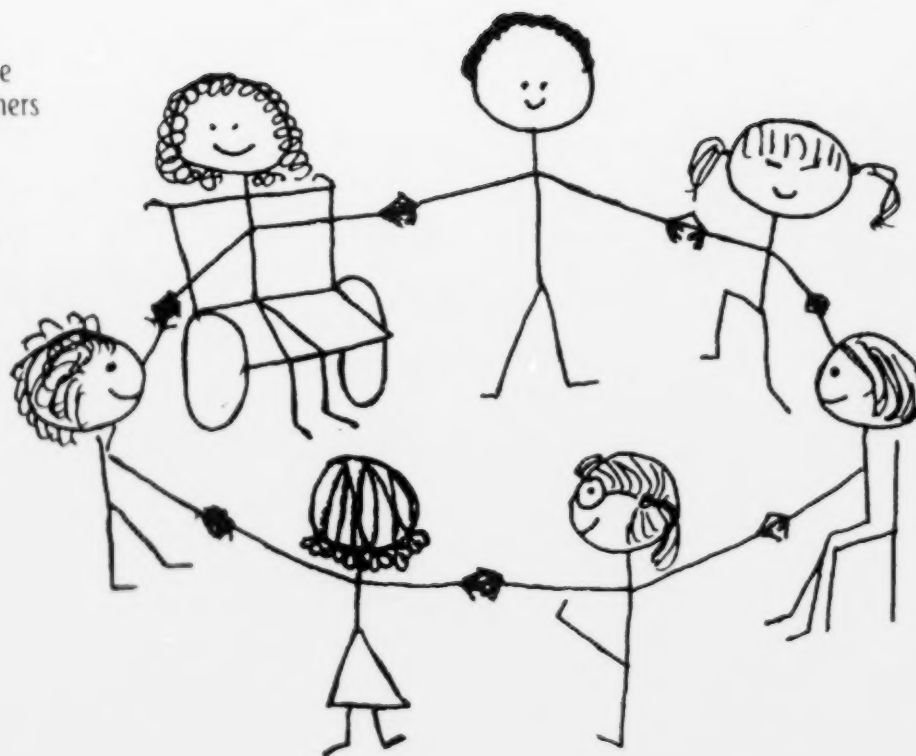
trainers are encouraged to use their own words and illustrations rather than reading the phrases from the manual.

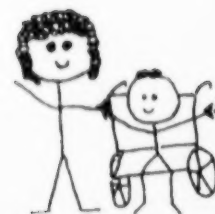
In developing the **Trainer's Workshop Manual**, Partners took great care to avoid language that creates or reinforces negative stereotypes of people with special needs. When paraphrasing these notes or making other comments, trainers should use language that conveys positive and respectful images of people with special needs. Trainers are encouraged to always choose words that emphasize the person, not his or her condition, disability, or special health needs.

The **Trainer's Workshop Manual** includes master copies of overheads and supplemental materials in the back of each section. Trainers can easily copy overheads onto transparencies. An effective training method used in several years of field testing is the *Suggested Overheads*. To help trainers use the overheads appropriately, Partners coded them. On the bottom right of every page is a code beginning with PP. Following the PP is a number that identifies the section where the trainer uses the overhead. The next number is the sequential number of the overheads in that section. Thus, the code "PP 2-3" is the third overhead of the second section covered in the workshop.

Use of this Manual

Partners provide instructions on the use of the *Supplemental Materials* in each section. Trainers make copies of these materials for each participant in the workshop. Again, at the bottom of each page of the *Supplemental Materials* is a code to help trainers use these materials appropriately. The code begins with PP and follows with SM, meaning *Supplemental Materials*. The next letter or number is the section where the trainers uses the material. The final number is the sequential number of *Supplemental Materials* in that section.





Preparation for Training

Preparation is key to an effective Partners workshop. Trainers should become acquainted with the Partners' workshop materials, including this manual and the **Family and Caregiver Manuals**. An accessible training facility with adequate size rooms, tables, and chairs for participant activities is necessary for a successful workshop.

If your Partners' workshop includes child care for families, then trainers must plan for this. Child care spaces should be in the same facility as the Partners' workshop for adults. Caring for children in a range of ages, with varying developmental needs, will require appropriate spaces, toys and supplies.

Trainers familiar with their communities' Partners program will help ensure smooth linkages for families, caregivers, and community contacts for support to those participating in the workshops.

Trainers should gather all materials and resources, including handouts and overheads, before the workshop. Familiarity with the **Trainers' Workshop Manual** and the **Family and Caregiver Manuals** will help trainers learn the content and flow of the workshop, and will prepare trainers to help participants with questions and concerns.

Workshop materials, including overheads handouts, and training manuals should be prepared before the workshop. Partners included master copies of overheads and handouts in this manual.

Partners included master copies of the **Family and Caregiver Manuals** in the step-by-step **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**. Trainers may purchase additional manuals from Child Development Resources in Norge, Virginia. A purchase order form is among the *Supplemental Materials* provided at the end of the Welcome to Partners Workshop Section.

Participants need an agenda that guides them through the workshop and increases their comfort by letting them know what to expect. At the end of the Welcome Section, among the *Supplemental Materials* are a one day and two-day sample agenda. Agendas should be prepared before the workshop.

Partners include sample evaluation measures as *Supplemental Materials* at the end of the Welcome Section. Trainers working with Partners staff, for replication of the Partners model use these evaluations. Instruments specific to the workshop should be prepared before training. Data from these measures give trainers information on how well participants reached the workshop objectives.

Partners developed a *Workshop Checklist* to help trainers prepare for workshops. The checklist is with the *Supplemental Materials* at the end of the Welcome Section.

About Overheads

The overheads contained in the Trainer's Workshop Manual were developed using proven methods to promote visual learning. Trainers may copy these overhead pages onto transparencies and may develop their own overheads for use in the workshop. Cartoons or drawings, in particular, can help make points clear or reinforce the presented information.

Effective visual aids enhance learning and reinforce essential information. Trainers who do not have access to an overhead projector may choose to copy the content of the included overheads onto flip chart pages. When trainers create their own overheads or flip chart pages, we hope they will follow these tips for effective visual aids:

- follow the participant manuals or handouts,
- reinforce or clarify one idea,
- stimulate thinking, discussion, and
- are simple and easy to read.

When using overheads, remember to:

- check the projector before training,
- keep an extra light bulb and extension cord on hand,
- position the projector so that all participants have a clear view of the screen,
- organize overheads for easy access during training,
- stand facing participants, reading from the machine or notes and not from the screen,
- use a pointer or cover portions of an overhead so that participants can easily follow the presentation, and
- give participants time to read each overhead before removing it from the screen.

Source:

The Great Lakes RAP. (1993). Train the Trainers. Foxon

Use of this Manual

About Handouts

Partners have included handouts in the *Supplemental Materials* in some sections of the manual. Trainers who choose to develop additional handouts may find the following tips helpful. Effective trainers:

- color code handouts for easy reference,
- distribute handouts essential to discussion before presenting
- save supplemental handouts for distribution after training,
- get permission to reproduce copyrighted material, and credit original authors, and
- ensure that copies are clear and readable.

Adapted from Wolfe, 1996.



30
mins

Welcome to the Partners Workshop

Objectives

- Register participants, introduce trainers, explain Partners Plus role
- Introduce participants, encourage interaction
- Outline workshop agenda

Preparations

Read the Introduction section of the **Family and Caregiver Manuals** carefully. Be familiar with this content.

Determine the number of participants. Prepare enough workshop materials for the group, including **Family Manuals**, **Caregiver Manuals**, workshop agendas, and photocopies of:

- Registration / Sign-In Sheet
- Initial Family Survey
- Caregiver Comfort Scale
- Caregiver Knowledge Scale

- What Did You Think of Training
- Get-To-Know-You Bingo (for groups of 10 or more only)

These forms are provided within the *Supplemental Materials* at the end of this section.

Prepare overhead transparencies of:

- Overhead Partners Plus PP W-1
- Overhead Partners Welcome (Part 1) PP W-2

Corresponding Sections

The content of this section corresponds with sections in the **Family Manual** or the **Caregiver Manual**.

3
mins

Registration

Distribute the following materials to the group:

- Registration / Sign-In Sheet
- Initial Family Survey
- Caregiver Comfort Scale
- Caregiver Knowledge Scale

Allow participants sufficient time to register and complete forms. The information families and caregivers supply in their pre-evaluations (Initial Family Survey, Caregiver Comfort and Knowledge Scales) will provide you with helpful information about their experience, knowledge, and comfort levels prior to the workshop.

Once participants have completed their paperwork, distribute the following course materials:

- Workshop Agendas
- Workshop Manuals

This activity is not scripted.

This activity does not require overheads.



10
mins

Introductions

Introduce yourself. Tell your connection with the agency or organization sponsoring the Partners workshop.

Give participants a brief history of Partners Plus.

Hello, and welcome. My name is _____, and I'm a trainer for Partners Plus. Today's workshop is supported by ...

The original Partners Plus project, developed at Child Development Resources in Norge, Virginia, was initially funded by a grant from the U.S. Department of Education (#H024B40032). That Partners Plus project designed a model to help families find and train respite caregivers for their child(ren) with special needs. Four manuals were created to support families, caregivers, trainers, and community planners in implementing this model. With subsequent outreach funding from the U.S. Department of Education (#H324R990006) and using a train-the-trainer approach, the Partners project now helps communities across the country replicate this

This activity does not require overheads.



Introductions continued

Display overhead and summarize the information it contains.

Summarize the goals of the workshop.

model for young children with disabilities. Funding from the Joseph P. Kennedy, Jr. Foundation has supported the adaptation of the four Partners manuals to meet the needs of communities serving older children with mental retardation and related developmental disabilities.

The original program was called *Partners Plus: Families and Caregivers in Partnerships*, and was developed using interviews and feedback from families.

We will go over the workshop agenda in a few minutes. When the workshop is over, individual families will have information and strategies to find and train caregivers for their children. Potential caregivers will have basic information and skills to work with families in respite.

Overhead Partners Plus 1-1

Partners Plus: Families and Caregivers in Partnerships

- Developed with feedback from families at Child Development Resources
- Families needed a break but did not feel comfortable with available options
- Families wanted to find and train their own respite caregivers

Introductions continued

Give participants a brief history of the agency or organization supporting the workshop. If more than one group is sponsoring the program, speak about each group.

In your description, be sure to answer the following questions:

- How does Partners fit the mission of your group?
- Who does your agency or organization serve?
- What other relevant services does your agency or organization provide?

Today's workshop is supported by _____ (agency or organization). Our purpose is to . . .

The Partners Plus program fits the mission of our group because . . .

We primarily serve . . .

We provide a number of services, such as . . .

This activity does not require overheads.

Introductions continued

Allow each of the trainers to introduce themselves. Have them explain their connection with the sponsoring organization.

Next, have those trainers that feel comfortable doing so share any personal or professional experiences with children with special needs, their families, and their caregivers.

Review housekeeping items, such as where restrooms are located, to help participants feel more comfortable with their training environment.

Reinforce your desire to allow open, active participation.

Hello. My name is _____ ,
and I'm also a trainer for Partners Plus. I
work with the sponsoring group by ...

Having worked with families with children
with special needs for many years, I am
very in tune with the issues families face
in caring for their child ...

Restrooms are located ...
Water fountains and soda machines are
located ...
Feel free to help yourselves to some light
refreshments, located ...

Feel free to ask questions or let us know
your thoughts at any point during the
discussion. We do have a lot to cover,
however, and may have to limit conversation
in the interest of time.

This activity does not require overheads.

10
mins

Icebreaker Activity

Choose your icebreaker: Round Robin or Get-To-Know-You Bingo (used with a workshop audience of 10 or more).

If Round Robin:

Introduce the activity and explain the rules.

Now that we have introduced ourselves, we want to learn a little bit about you. We would like to go around the room and have you introduce yourselves. Tell us your name and a little bit about why you are here.

If Get-To-Know-You Bingo:

Introduce the activity and explain the rules.

Now that we have introduced ourselves, we want to learn a little bit about you. We're going to play a game to get everyone moving and talking to each other. It's called Get-To-Know-You Bingo. It's played just like Bingo, but with a twist.

Distribute copies of Get-To-Know-You Bingo. Have participants wait to begin until all instructions are given.

In Bingo, you mark boxes on your card as each letter is called. Here, you mark a box on your card when a person tells you that she or he fits the description in that box. Write the person's name in the box so that you remember what you know about him or her. When you have a row of names, call out "Bingo!"

Icebreaker Activity continued

If Get-To-Know-You Bingo:

When everyone understands the rules, have them begin. Encourage participants to speak to more than one person.

This activity is not scripted.

This activity does not require overheads.

When someone calls "Bingo," announce that there is one winner. If time permits, play a second round for another winner.

At the end of the game, have everyone return to their seats. Ask the winners to introduce the people they marked on their cards.

If possible, present small prizes to winners, such as pencils, candy, or certificates.

3
mins

Review the Workshop Agenda

Refer participants to their agendas.

This activity is not scripted.

Briefly describe the sections on the agenda for Part 1 and summarize the objectives of each section.

Review the plan for the break between Part 1 and Part 2. Determine how you will handle the break—eat together, move into a separate space for meals, etc.

Note: If Part 1 and Part 2 are held on different days, review the information about Part 2 at both the end of the first day (end of Part 1) and the beginning of the second day.

Overhead 1-2 Partners Workshop (part 1)

Partners Workshop (Part 1)

Welcome and Introductions

About the Partners Model

Communication

Families and Caregivers Working Together

All Kids Like Cookies Activity

Review the Workshop Agenda continued

Briefly describe the sections on the agenda for Part 2 and summarize the objectives of each section.

This activity is not scripted.

Overhead 1-3 Partners Workshop (Part 2)

Partners Workshop (Part 2)

Family Break-Out Session

Finding Respite
Caregivers

Interviewing
Caregivers

Developing a Personal-
ized Training Plan

Using Daily Routines to Develop a Training Plan

Caregiver Break-Out Session

Disabilities
Sensitivity

Child Development

Children with
Special Needs

Becoming a
Caregiver

2
mins

Review the Workshop Materials

Refer participants to their manuals.

We will be referring to your manuals throughout the workshop. Your manuals follow the flow of the workshop.

This activity does not require overheads.

We will highlight the essential information in your manuals during the workshop. However, we will not be able to cover everything. Your manuals will be yours to take with you after the workshop and to refer to as you build respite partnerships together.

5
mins

Answer Questions and Wrap Up

Conclude the section by answering questions.

We are looking forward to our workshop today! Do not hesitate to ask questions throughout the workshop or to let us know if you have additional needs.

Let's get started . . .

This activity does not require overheads.

Welcome to the Partners Workshop
Suggested Overheads

DRAFT 10.99

Partners Plus: Families and Caregivers in Partnerships

- Developed with feedback from families at Child Development Resources
- Families needed a break but did not feel comfortable with available options
- Families wanted to find and train their own caregivers



DRAFT 10.99

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Partners Plus Workshop

Family and Caregiver Manuals Section 1

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP W-1

Partners Plus: Families and Caregivers in Partnerships

Unit 1–Welcome and Introductions

Unit 2–About the Partners Model

Unit 3–Building Partnerships:
Communication

Unit 4–Families and Caregivers
Working Together

Unit 5–All Kids Like Cookies Activity

**Family Break-
Out Session**



Unit 6 Families–
Finding Respite
Caregivers

Unit 7 Families–
Interviewing Caregivers

Unit 8 Families–
Developing a Personalized
Training Plan



Unit 10–Using Daily Routines To Develop a
Personalized Training Plan

**Caregiver Break-
Out Session**



Unit 6 Caregivers–
Disabilities Sensitivity

Unit 7 Caregivers–Understand-
ing Child Development

Unit 8 Caregivers–Children
with Special Needs

Unit 9 Caregivers–
Becoming a Caregiver



DRAFT 10.99



Partners Plus Workshop

Family and Caregiver Manuals Section 1

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP W-2

Welcome to the Partners Workshop Supplemental Materials

DRAFT 10.99

Checklist of Materials and Equipment for Partners Workshop

Date: _____ Time: _____ Location: _____

Purpose: _____

Number Expected to Attend: _____ Presenter(s): _____

Room and Facility Preparation

- _____ Table for Registration
- _____ Table for Display Materials
- _____ Table Space for All Participants
- _____ Tables Arranged in a Horseshoe Shape
- _____ Chairs for All Participants
- _____ Extra Tables for "All Kids Like Cookies" Activity
- _____ Tables for Lunch or Refreshments (optional)
- _____ Overall Agenda for Training
- _____ Rooms for Childcare According to Numbers of Children Attending
- _____ Childcare Rooms with Accessibility to Lavatories (Preferably in Room)

Childcare Preparation

- _____ Caregiver Sign-In Sheet
- _____ Appropriate Toys and Activities
- _____ Activity Supplies
- _____ Snacks
- _____ First Aid Kit
- _____ "Partners Plus Workshop Childcare Information"

Getting Started

- _____ Refreshment Supplies (optional)
- _____ Name Tags or Tents
- _____ Sign-In Sheets
- _____ Initial Family Survey

Getting Started, continued

- _____ Comfort Measure-Pre
- _____ Knowledge Measure-Pre
- _____ Participant's Manuals
- _____ Overall Agenda for the Training
- _____ Getting Acquainted Activity
- _____ Pencils for Participants
- _____ Sample Press Release and Feature Articles form (optional)
- _____ Permission for Videotape with Sound / Photo Use (Enough for All Participants)

Section 1

- _____ Handouts
- _____ Prepared Overhead Transparencies / Flip Charts
- _____ Overhead Projector and Screen (optional)
- _____ Markers for Either Flip Charts or Overhead Transparencies
- _____ Flip Chart Stand
- _____ Incentives for Participation in Methods of Communication Activity

Section 2

- _____ Prepared Overhead Transparencies / Flip Charts
- _____ Overhead Projector and Screen (optional)

Workshop Materials, continued

Section 2, continued

- ___ Markers for Either Flip Charts or Overhead Transparencies
- ___ Flip Chart Stand
- ___ Incentives for Participation in Methods of Communication Activity

Section 3

- ___ Prepared Overhead Transparencies / Flip Charts
- ___ Overhead Projector and Screen (optional)
- ___ Markers for Either Flip Charts or Overhead Transparencies
- ___ Flip Chart Stand

Section 4

- ___ Handouts
- ___ Enough of the Easy and Hard Version of the XYZ Tests (Equal Number of Each) for All Participants
- ___ Method for Dividing Participants into Groups of Equal Number (for the "All Kids Like Cookies" Activity)
- ___ Directions for Each Station
- ___ Props for the "All Kids Like Cookies" Activity

Vision Station: several pairs of prepared sunglasses, blindfolds, a page out of a coloring book or a crossword puzzle, crayons, children's books and magazines, plastic cup and pitcher with water, paper towels

Speech Station: marshmallows, gauze, trash can, paper towels

Fine Motor Station: several pairs of thick gloves, masking tape, puzzles, small manipulative toys, thick string and beads or pasta

Gross Motor Station: two large balls, two retrievable toys, masking tape, use masking tape to make two ten to fifteen foot walkways

Section 4, continued

- ___ Prepared Overhead Transparencies / Flip Charts
- ___ Overhead Projector and Screen (optional)
- ___ Markers for Either Flip Charts or Overhead Transparencies
- ___ Flip Chart Stand

Section 5-F

- ___ Overhead Transparencies / Flip Charts Developed by Trainers (optional)
- ___ Overhead Projector (if needed)
- ___ Flip Chart Stand (if needed)

Section 5-C

- ___ Prepared Overhead Transparencies / Flip Charts
- ___ Overhead Projector
- ___ Flip Chart Stand

Section 6-F

- ___ Overhead Transparencies / Flip Charts Developed by Trainers (optional)
- ___ Overhead Projector (if needed)
- ___ Flip Chart Stand (if needed)

Section 6-C

- ___ Prepared Overhead Transparencies / Flip Charts
- ___ Overhead Projector
- ___ Flip Chart Stand

Section 7-F

- ___ Overhead Transparencies / Flip Charts Developed by Trainers (optional)
- ___ Overhead Projector (if needed)
- ___ Flip Chart Stand (if needed)

Partners Workshop Agenda

Date

Location

Time

Part II

Time Registration and Light Refreshments

Time Activity: All Kids Like Cookies

Time Break Out Session for Families
Finding Respite Caregivers
Interviewing Caregivers
Developing an Personalized Training Plan

Time Break Out Session for Caregivers
Understanding Child Development
Disabilities Awareness
Children with Special Needs
Becoming a Respite Caregiver

Time Break - 5 minutes
Practice Activity: Using Daily Routines
Wrap up and Evaluations

Time Congratulations! You are on your way!

Partners Workshop Agenda

Date

Location

Time

Part I

Time Registration and Light Refreshments

Welcome and Introductions

About Partners

Communication

Time Break - 5 minutes

*Building Partnerships: Families and
Caregivers Working Together*

Preview of Coming Attractions

Time See Ya for Part 2!

Partners Workshop Agenda

Date
Location
Time

Part II

- Time Registration and Light Refreshments*
- Time Activity: All Kids Like Cookies*
- Time Break Out Session for Families*
Finding Respite Caregivers
Interviewing Caregivers
Developing an Personalized Training Plan
- Time Break Out Session for Caregivers*
Understanding Child Development
Disabilities Awareness
Children with Special Needs
Becoming a Respite Caregiver
- Time Break - 5 minutes*
Practice Activity: Using Daily Routines
Wrap up and Evaluations
- Time Congratulations! You are on your way!*

Partners Plus Workshop Sign-In Sheet

Location: _____

Date: _____

Trainers: _____

Name	Address	Phone	How did you hear about Partners Plus?	Are you a Family or Caregiver?

DRAFT 10.99

Partners Plus Initial Family Survey

Please describe any special needs your child might have. If you have more than one child, you may use the space on the back.

Child's Name: _____ Age: _____

1. Does your child have any special needs such as: developmental delay, multiple disabilities, vision, hearing, feeding, behavior, heart problems, breathing problems, other? If so, please explain.

2. Has your child received early intervention, special education, or therapeutic services? If so, please explain.

3. Does your child use any assistive technology such as: electric wheelchair, medical equipment, communications board, other? Please describe.

Initial Family Survey continued

Answer the following questions if you have ever left your child in another person's care. Please circle the best answer.

- | | | | | | |
|--|-----------------------|------------------|-------------------------|----------|---------------------|
| 4. In general, how hard has it been to arrange respite (temporary child care) for your child(ren)? | Not Difficult
1 | 2 | Somewhat Difficult
3 | 4 | Very Difficult
5 |
| 5. How comfortable did you feel leaving your child(ren) with the caregiver? | Not Difficult
1 | 2 | Somewhat Difficult
3 | 4 | Very Difficult
5 |
| 6. Have you ever taught a caregiver to care for your child? | Yes | No | | | |
| 7. How much time did you spend teaching the person how to care for your child? | Less than
30 mins. | About
3 hours | Over
3 hours | | |
| 8. In the last three months, how often have you used respite care? | 0 | 1-3 | 4-6 | 6 and up | |
| 9. In the last three months, how often did you want respite, but could not find a caregiver? | 0 | 1-3 | 4-6 | 6 and up | |
| 10. In the last three months, how many times did caregivers cancel? | 0 | 1-3 | 4-6 | 6 and up | |

Please answer the following questions about your family members. This information is optional.

11. Child's Mother's Age _____ Child's Father's Age _____

12. What is the child's mother's highest level of education?

- | | |
|--|---|
| ☐ Middle School | ☐ College Graduate (4 years) |
| ☐ High School | ☐ Some Graduate School |
| ☐ Some College | ☐ Graduate Degree |

13. What is the child's father's highest level of education?

- | | |
|--|---|
| ☐ Middle School | ☐ College Graduate (4 years) |
| ☐ High School | ☐ Some Graduate School |
| ☐ Some College | ☐ Graduate Degree |

Partners Plus Caregiver Comfort Scale Pre Evaluation

Please circle the number that best describes how comfortable you feel in working with children with special needs.

<i>How comfortable are you:</i>	Very Uncomfortable			Very Comfortable	
Providing care for a child with special needs.	1	2	3	4	5
Planning activities that a child with special needs can enjoy.	1	2	3	4	5
Meeting the routine health care needs of a child with special needs.	1	2	3	4	5
Feeding a child with special needs.	1	2	3	4	5
Talking with families of children with disabilities about their child and their child's strengths and needs.	1	2	3	4	5
Talking to other people about any concerns they may have about children with special needs in your care.	1	2	3	4	5
Identifying resources and getting help you may need in caring for children with special needs.	1	2	3	4	5

Thank You !

Partners Plus Caregiver Knowledge Pre Evaluation

Name: _____ Date: _____

This survey is designed to gather information about your experience and knowledge of caring for children with disabilities or special needs.

Read each statement and circle the single best answer.

1. Early intervention services are available to children with disabilities who are
 - a. Birth to three years old
 - b. In public schools
 - c. Three to five years old
 - d. I don't know
2. Children who receive early intervention special education services must
 - a. Get therapy
 - b. Go to a classroom program
 - c. Have an individual plan
 - d. I don't know
3. All children with special needs receive education through
 - a. MCH
 - b. CHIP
 - c. IDEA
 - d. I don't know
4. Which of these diagnoses tells you that a child has a special health care need?
 - a. Autism
 - b. Cystic Fibrosis
 - c. Mental retardation
 - d. I don't know
5. Providing good respite care for a child with a disability depends heavily on
 - a. Desire/attitude of caregivers
 - b. Educational level of the caregiver
 - c. A child's disability
 - d. I don't know
6. When caring for children with disabilities in their homes, it is necessary to
 - a. Learn about their daily household routines
 - b. Change things to suit your way of providing care
 - c. Ignore the way the family trained you to take care of the child
 - d. I don't know

7. A key to a successful respite care program for families is
- a. Providing each family with many caregivers
 - b. Allowing each family to train their own caregivers
 - c. To start more respite agencies
 - d. I don't know
8. It is most important for respite caregivers to
- a. Understand child development
 - b. Know the needs of the child or children in their care
 - c. Have a degree or certification
 - d. I don't know
9. The term "cognitive development" is used to describe how a child
- a. Relates to others
 - b. Sits and grasps toys
 - c. Thinks and solves problems
 - d. I don't know
10. If caregivers have questions or concerns about a child's special needs, they should
- a. Discuss their concerns with the child's parent(s) or guardian
 - b. Call the local special education program
 - c. Not do anything because if they are wrong it would upset the child's parents
 - d. I don't know

Thank You!

What Did You Think About the Workshop?

Name: _____ Date: _____

Presenter(s): _____

1. What I liked about the workshop...

2. How Did We Do? The information presented was:

_____ easy to understand

_____ difficult to understand because...

3. The information presented was:

_____ useful

_____ not useful because...

- | | | | | | |
|--|------------|---|---|---|-----------|
| 4. The overall quality of the workshop was: | 1 | 2 | 3 | 4 | 5 |
| | Very Poor | | | | Very Good |
| 5. Were the workshop materials helpful? | 1 | 2 | 3 | 4 | 5 |
| | Not at All | | | | Very |
| 6. Was the information presented appropriate for your needs? | 1 | 2 | 3 | 4 | 5 |
| | Not at All | | | | Very |
| 7. Was there enough chance for questions and discussion? | 1 | 2 | 3 | 4 | 5 |
| | Not at All | | | | Very |

8. I gained knowledge about...

9. Suggestions I would like to offer for improving the workshop...

10. I think what I'll remember most was...

11. Please share any additional comments:

Get-To-Know-You Bingo!

B	I	N	G	O
Volunteers at least once a week	Sings in a choir	Exercises to cope with stress	Can define respite	Works with persons with disabilities
Grew up in another state	Knows what IDEA stands for	Would rather draw a picture than write a story	Makes it a policy to laugh at least once a day	Loves to play with play dough!
Has a family member with special needs	Loves it when it snows!	FREE	Has younger brothers/sisters	Is carrying pictures of his/her family
Hates to sit still	Has no extended family in the area	Hasn't seen a movie in a theater for over two years	Wears contacts or eye glasses	Is a member of a nontraditional family
Considers her/himself creative	Has never worked with someone with special needs	Enjoyed elementary school	Is certified in CPR	Has a pet

Partners Plus Order Form for Printed Materials

Name: _____

Title, Company: _____

Street Address: _____

City, State, Zip: _____

Telephone: _____ Fax: _____

Quantity	Item Number/ Description	Unit Cost	Total

Subtotal _____

Shipping and Handling _____

Total _____

Method of Payment:

Check number: _____ P.O. number: _____

Visa or Mastercard number (\$25 Minimum Charge): _____

Expires: _____ Signature: _____

Shipping and Handling Charges:

Orders totalling \$1.00 to \$49.99	\$7.00	Additional Fees required for international and priority delivery service
Orders totalling \$50.00 to \$99.00	\$10.00	
Orders totalling \$100.00 or more	\$12.00	

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Return Completed Form To:

Child Development Resources, 1490 Government Road, Williamsburg, VA 23185
Phone (757) 220-1168 · Fax (757) 253-1779 · Email: ppcdr@tni.net

30
mins

Section 1—About Respite

Objectives

- Introduce participants to respite and describe the Partners model of respite care
- Define respite care and identify the benefits to families, caregivers and children
- Demonstrate how families drive family-centered services
- Explain the rights and responsibilities individuals have as participants in family-centered systems
- Ensure participants understand the Partners model of respite care

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 1, "About Respite," in the **Family and Caregiver Manuals**.

Prepare overhead transparencies of:

- Overhead Partners Plus What is Respite Care? 1-1
- Overhead Partners Plus Benefits of Respite to Families 1-2
- Overhead Partners Plus Benefits of Respite to Children 1-3
- Overhead Partners Plus Benefits of Respite to Caregivers 1-4
- Overhead Partners Plus Why Don't Families Use Respite Care? 1-5
- Overhead Partners Plus Partners . . . 1-6
- Overhead Partners Plus Partners Model Steps 1-7
- Overhead Partners Plus What Respite Means 1-8

Corresponding Sections

Please refer participants to Section 1, "About Respite," in the Partners Plus **Family and Caregiver Manuals**.

10
mins

Respite

The goal of this activity is to involve participants in discussion early in the program and to get them interested and excited about respite and the Partners model.

Introduce the concepts of the section. Refer to overhead Partners Plus What is Respite Care? 1-1.

Help participants understand the difference between respite and respite care: respite care is child care that gives families a break (respite).

Let's begin by discussing what we mean when we are talking about respite and respite care. The term "respite" means relief, or to take a break.

"Respite care," then, is occasional child care that gives families respite, or a break from the daily demands of raising children with special needs.

All families need a break, but families who have children with special needs may have a more difficult time finding reliable, responsible caregivers.

Overhead Partners Plus 1-1

What is Respite Care?

- Respite care is occasional child care that gives families a break (that gives families *respite*) from the daily demands of raising children with special needs.

Respite continued

Benefits of Respite to Families

Introduce the benefits of respite for each participant.

Ask the group to talk about how family members benefit from time away. Give families and caregivers a few minutes to generate answers.

As people share comments, they are educating each other. Affirm their answers: respite can be everything for families that they want it to be.

You may need to stimulate the conversation with a few examples. Sharing your own personal experience is best.

There are three participants in respite relationships: family members, the children with special needs who are receiving care, and respite caregivers. Let's take a minute to consider how each member of the respite relationship benefits from this experience.

How might individual family members benefit from time away from caring for a child with special needs?

How might they spend their time, their respite?

What about resting, entertaining themselves, shopping, pampering each other? What else?



Respite continued

Refer to overhead Partners Plus Benefits of Respite to Families 1-2. Reveal information one line at a time in order to stimulate discussion.

Briefly highlight the benefits of respite that participants do not list. Refer them to Section 1 in the Partners Plus Family and Caregiver Manuals.

Benefits of Respite to Children

Introduce a few ways in which children with special needs also benefit from respite care.

Ask the group to list other ways children with special needs might benefit from respite. Again, take a few minutes to generate responses.

Excellent. Those are all benefits of respite. What are some others? Pursuing interests, spending time with other family members and friends?

Great. Let's go over a few more ways that families can benefit from respite, like . . .

It's not just families who benefit from respite; children benefit also.

Respite gives the child the opportunity to interact with new people and develop social skills. Respite also introduces children to different caregivers, who bring different experiences. Children feel a sense of relief when their families get a break.

Overhead Partners Plus 1-2

Benefits of Respite to Families

- R est
- E ntertainment
- S hopping
- P ampering
- I nterests
- T ime
- E verything Families Want it To Be



Respite continued

Refer to overhead Partners Plus Benefits of Respite to Children 1-3. Reveal information one line at a time in order to stimulate discussion.

Briefly highlight the benefits of respite that participants do not list. Refer them to Section 1 in the Partners Plus Family and Caregiver Manuals.

Benefits of Respite to Caregivers

Introduce the benefits of respite to caregivers as a starting point for discussion.

Did you know that after providing respite, caregivers often say that they learn far more from the children they work with than those children learn from them?

Respite gives children with special needs the opportunity to teach others about their experience. It also helps send the message that children with special needs are not so different from other children.

The third group to benefit from respite care are the caregivers themselves. Caregivers meet some amazing children and families, and make an important difference in their lives.

Respite care encourages caregivers to learn new skills, such as sign language. Some caregivers view respite as a job, and value the working experience.

Overhead Partners Plus 1-3

Benefits of Respite to Children

- R elief
- E xploration
- S pecial friends
- P arents feel rejuvenated
- I nteraction
- T ime for independence
- E ducate others



Respite continued

Ask participants to list benefits of the respite experience.

Refer to overhead Partners Plus Benefits of Respite to Caregivers 1-4. Refer participants to Section 1 in the Partners Plus Family and Caregiver Manuals.

Wrap up the discussion.

What are some other ways caregivers might benefit from providing respite?

So, all three of the members of a respite relationship can and should benefit from the respite experience. Respite is important to the well-being of children and families, and caregivers can feel confident that what they are doing is important, life-enriching work!

Overhead Partners Plus 1-4

Benefits of Respite to Caregivers

- **R** eally great children and families
- **E** specially rewarding
- **S** elf-improvement
- **P** ositive attitudes
- **I** nvolvement
- **T** ruly appreciated
- **E** verything they want

Respite continued

Barriers for Families Who Want Respite Care

Introduce this section by asking this question:

Discuss potential barriers to respite.

Refer to overhead Partners Plus Why Don't Families Use Respite Care? 1-5 during the discussion. Refer participants to Section 1 in the Partners Plus Family and Caregiver Manuals.

So, if respite is so wonderful, why aren't families using respite care?

It can be very hard to find a trusted, familiar person who is willing to provide care, particularly with the training and the commitment families are looking for.

Sometimes, caregivers cancel. Planning for respite care can be far more energy- and time-consuming than planning for other child care. Imagine how it would feel to do all of that planning and get excited about having some time away, only to have a caregiver cancel at the last minute.

Also, families expect a lot from themselves, and may feel guilty that they need a break. And, finding community respite programs can be difficult.

Overhead Partners Plus 1-5

Why Don't Families Use Respite Care? Families . . .

- Struggle to find caregivers
- Fear leaving children with strangers
- Think caregivers don't have enough training
- Feel guilty
- Can't find community programs
- Feel too disappointed when caregivers cancel

15
mins

The Partners Model

Introduce the section by explaining the Partners concept. Review the overhead to outline the components.

Refer participants to Section 1 in the Partners Plus **Family and Caregiver Manuals** for a definition of "family-centered."

Refer to overhead Partners Plus 1-6 Partners . . . Participants may follow along in Section 2 of their manuals.

The Partners model of respite training was developed in response to the barriers and concerns identified by families. Families also identified components that are essential to a successful respite program.

First, Partners is a family-centered model. When we say family-centered, we mean that we recognize the family as the constant in a child's life. We believe that services like ours must support the child by supporting, respecting, and encouraging the family.

We do this by giving families options for how they participate, who their caregivers are, how they are trained, and how respite is provided. We support families in finding caregivers and in training them. By doing this, we hope to expand respite options for families.

How does Partners achieve these goals?

Overhead Partners Plus 1-6

Partners . . .

- is a family-centered model
- offers families choices
- supports families and caregivers
- helps families and caregivers build skills to communicate
- helps families and caregivers build long-term relationships

The Partners Model continued

Refer participants to overhead Partners Plus 1-7 Partners Model Steps.

Note: As you discuss Step 3, be sure to describe briefly how your community's Partners Plus program supports families and caregivers as they try to make matches.

There are five steps in the Partners model. In Step 1, the project recruits potential caregivers and families for participation in the program.

In Step 2, families and caregivers attend a workshop, which is the first part of the training process. At the workshop, families learn to find, screen and train their own caregivers. Meanwhile, caregivers get basic information on working with children with special needs and their families.

In Step 3, the program helps families choose caregivers who they want to provide respite care for their children. Families are best able to choose caregivers for their children. Likewise, caregivers are best able to decide who they will be successful with. The Partners program provides families and caregivers with information and resources to interview each other and make choices about working together.

Overhead Partners Plus 1-7

Partners Model Steps

- | Partners Model Steps | |
|----------------------|---|
| Step 1 | Recruit families and caregivers |
| Step 2 | Conduct Partners workshop |
| Step 3 | Help families choose caregivers |
| Step 4 | Guide families as they train their own caregivers |
| Step 5 | Provide continuing support |

The Partners Model continued

Note: As you discuss Step 4, be sure to describe briefly how your community's Partners Plus program supports families and caregivers in personalized training.

In Step 4, the Partners program assists families as they train their own caregivers. In workshops, we give caregivers basic information on working with children with special needs and their families. After group training, families, who know their children best, teach caregivers about their particular children. At the same time, we give families a structure for giving caregivers training specific to their children. We call this training "personalized training."

Finally, in Step 5, Partners provides continuing support in two ways. First, Partners is available to families and caregivers as they work together in respite. Second, Partners staff ensure that this respite program is continued in the community.

Overhead Partners Plus 1-7

Partners Model Steps

- | | |
|--------|---|
| Step 1 | Recruit families and caregivers |
| Step 2 | Conduct Partners workshop |
| Step 3 | Help families choose caregivers |
| Step 4 | Guide families as they train their own caregivers |
| Step 5 | Provide continuing support |

5
mins

Summary

Conclude the section by asking if there are any questions or comments about respite or the Partners model.

You may need to curtail discussion politely in order to keep within the time allotted.

Refer to overhead Partners Plus 1-8 What Respite Means.

Any questions or final thoughts on respite or the Partners model that you'd like to share with the group?

Great. In closing this section, I want to bring it back to the importance of respite for families. This quote is from a father who participated in Partners: "Think of a candle that slowly burns, the flame flickers and goes out, and just as a candle, we need to be relit too."

Respite is a lifesaver for many families, and respite care is an important job for caregivers who want to make a difference!

Overhead Partners Plus 1-8

What Respite Means

"Think of a candle that slowly burns, the flame flickers and goes out, and just as a candle, we need to be relit too."

— A Parent

Section 1—About Respite Suggested Overheads

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What Is Respite Care?

Respite care is occasional child care that gives families a break from the daily demands of raising children with special needs.



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PP 1-1

Benefits of Respite to Families

R est

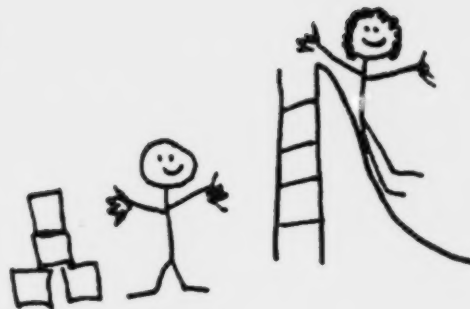
E ntertainment

S hopping

P ampering

I nterests

T ime



E verything you want it to be!

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PP 1-2

Benefits of Respite to Children

R elief

E xploration

S pecial friends

P arents feel rejuvenated

I nteraction with other people

T ime to be independent

E ducating others



DRAFT 10.99



Benefits of Respite to Caregivers

R eally great children
and families

E specially rewarding

S elf-improvement

P ositive attitudes

I nvolvement

T horoughly appreciated

E verything you want it to be!



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Why Don't Families Use Respite Care?

Families . . .

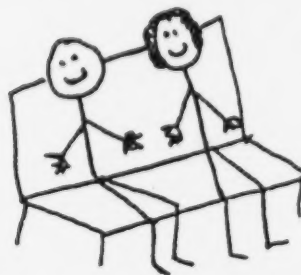
- struggle to find caregivers
- fear leaving children with strangers
- think caregivers don't have enough training
- feel guilty
- can't find community programs
- feel too disappointed when caregivers cancel

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Partners . . .

- is a family-centered model
- offers families choices
- supports families and caregivers
- helps families and caregivers build skills to communicate
- helps families and caregivers build long-term relationships



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PP 1-6

Partners Model Steps

**Step 1 Recruit families
and caregivers**

**Step 2 Conduct initial
workshop**

**Step 3 Help families
choose caregivers**

**Step 4 Support families
as they train their
own caregivers**

**Step 5 Provide continuing
support**

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Partners Plus Workshop

Family and Caregiver Manuals Section 1

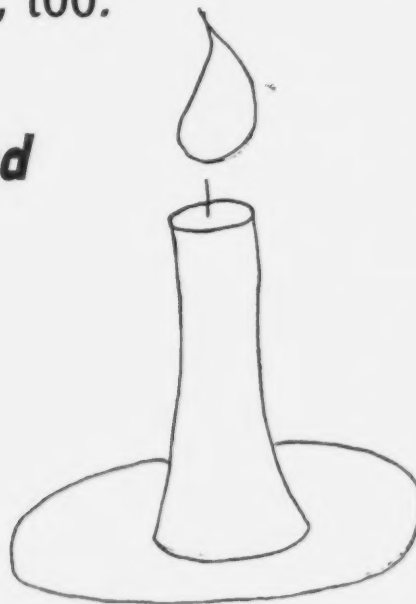
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PP 1-7

What Respite Means

“Think of a candle that slowly burns . . . the flame flickers and goes out. Just as a candle, we need to be re-lit, too.”

— ***A Dad***



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Family and Caregiver Manuals Section 1

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PP 1-8

45
mins

Section 2—Building Partnerships: Communication

Objectives

- Build communication skills
- Define the importance of clear and open communication in a respite relationship
- Identify the variety of ways that people send and receive messages
- Learn how to recognize and mend communication breakdowns

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 2, "Building Partnerships: Communication," in the **Family and Caregiver Manuals**.

Prepare overhead transparencies of:

- Overhead Partners Plus Communication Is . . . 2-1
- Overhead Partners Plus How Do You Feel? 2-2
- Overhead Partners Plus The Record 2-3
- Overhead Partners Plus Six Messages of Communication 2-4
- Overhead Partners Plus Non-Verbal Communication and Lifeways 2-5
- Overhead Partners Plus Building Partnerships Through Communication 2-6

Corresponding Sections

Please refer participants to Section 2, "Building Partnerships: Communication," in the Partners Plus **Family** and **Caregiver Manuals**.

8
mins

Introduction

Introduce this section by talking about how communication helps families and caregivers build lasting relationships with each other.

Our goal with Partners is to help families and caregivers build long-lasting respite relationships. We believe that communication and understanding are the most important tools to build these partnerships. In this section, we will talk about how communication works, and how it can be used in respite.

Refer to overhead Partners Plus Communication Is . . . 2-1. Participants may follow along in Section 2 in the Partners Plus **Family and Caregiver Manuals**.

When we talk about communication, we are talking about the way that information is passed from one person to another.

We communicate in a lot of different ways. Research tells us that we communicate 7% of our messages through the words that we use. We choose our words very carefully.

Overhead Partners Plus 2-1

Communication Is . . .

- 7% Words
- 38% Voice
- 55% Facial and Body Language

Introduction continued

Use an example from your experience to make this point.

Use some examples from the class to illustrate this point.

In the field of disability, we use many words that we do not use anywhere else. When people enter this field and try to communicate, they might feel like they are learning a new language. When caregivers and families work together, it is very important that they feel comfortable asking what words mean.

Even more important than the words that people choose is the voice that they use. You can use the very same words and communicate two different messages just by changing your voice. When we talk to people, we need to be aware of how we use our voices.

The most powerful way that we communicate is through our facial and body language. Though none of you are speaking to me right now, all of you are telling me something with your bodies and faces. For example, your posture is telling me . . .

Overhead Partners Plus 2-1

Communication Is . . .

- 7% Words
- 38% Voice
- 55% Facial and Body Language

141

8
mins

Non-Verbal Communication Activity

Introduce the activity.

Refer to overhead Partners Plus How Do You Feel? 2-2.

Explain the activity.

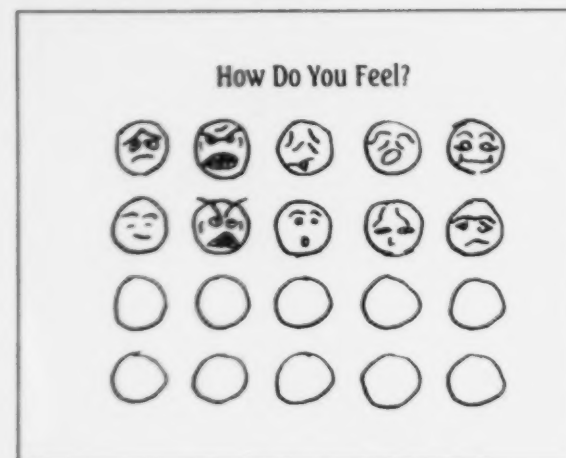
Give the group a minute to complete the activity. Then, divide the group into pairs. Ask the participants to guess the emotion that their partners drew. Spend two minutes on this.

Let's try to illustrate this point further. Please turn to page 2-4 of your manuals. We are going to do a short activity to help us better understand how we communicate with facial expressions and body language.

On your page, there are some faces and some blank circles. Think about an emotion that you were feeling before you came to training today—an emotion different from those shown here. Now, draw what you think your face looked like when it was expressing that emotion. Don't label your picture, just draw it.

Now let's divide into groups of two. Try to guess what emotion your partner drew.

Overhead Partners Plus 2-2



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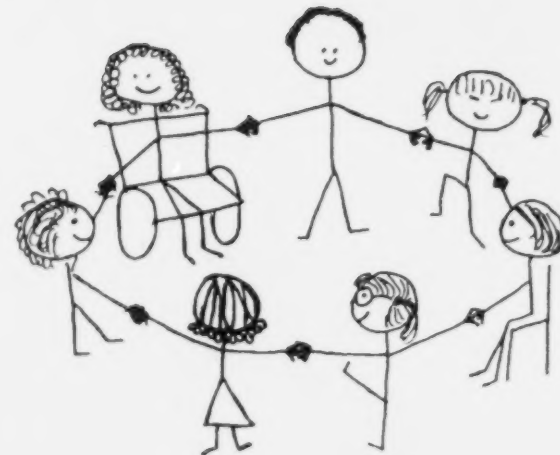
Non-Verbal Communication Activity continued

Ask participants to share what they learned. You might need to prompt with some questions to facilitate discussion.

Draw conclusions for the group.

How did you do? Did you find it easy to guess what emotion was drawn?

How many guessed correctly? For those who did: So the faces communicated clear messages to you. Sometimes, people have trouble interpreting the looks on people's faces. They might need to use words to clarify. They might say, "Oh, you look angry. Did I say something to upset you?" This is a good way to check to make sure that their perceptions are right.



25
mins

Building Communication Skills

Refer to overhead Partners Plus The Record 2-3.

Like faces, the same words can mean different things to different people. Here, the same sentence has different meanings for two people with two different definitions of the same word. Again, using words can help clarify. Families and caregivers can use the words "describe," "show me," and "tell me," to clarify misunderstandings.

Refer to overhead Partners Plus Six Messages of Communication 2-4. Participants may follow along in Section 2 in the Partners Plus Family and Caregiver Manuals.

When we think about communication, it makes sense to think of it as a process. There are many places that communication can break down. Sometimes, what people say is not what they mean. At other times, someone hears something different from what was said or misinterprets a message. Families and caregivers must pay attention to communication, and watch for misunderstandings. Feel free to ask again if you are confused about what the other person is communicating.

Overhead Partners Plus 2-3

The Record

- She has a great record! (music record)
- She has a great record! (data record)

Overhead Partners Plus 2-4

Six Messages of Communication

- What you mean to say
- What you actually say
- What the other person hears
- What the other person thinks he/she hears
- What the other person says
- What you think the other person says

Building Communication Skills continued

Refer to overhead Partners Plus Non-Verbal Communication and Culture 2-5. Participants may follow along in Section 2 in the Partners Plus Family and Caregiver Manuals.

Make the following points.

We know that communication is influenced by what we call our "life ways." People in different cultures, and even different families, learn their own ways of communicating.

When you are working with each other, remember that it may take some time for you to feel comfortable with each other's communication.

A lot of life ways differences in communication are nonverbal. For some people, too much silence can be uncomfortable. Other people need some pauses in conversation.

Different people think about body space differently too. In America, we usually feel comfortable talking to someone who is about a foot away from us. In other cultures, they prefer people to be closer when they are talking.

Overhead Partners Plus 2-5

Non-Verbal Communication and Culture Life Ways (Our Customs that Reflect Our Culture and Values)

- Reactions to silence
- Amount of space between bodies
- Eye contact
- Body postures
- Eyes that speak
- Presumed understanding that comes from similar experiences

Building Communication Skills continued

Make the following points.

For some people, eye contact conveys trust, like the person is listening and interested. In some cultures, however, eye contact is considered disrespectful.

Body postures can tell us a lot too. In America, an open body posture, where the arms are uncrossed, is more inviting than a closed body posture, with the arms crossed to block you.

People's eyes can be very expressive. Families often use glances to convey meaning. For example, some couples can look at each other from across a crowded room at a party and let each other know that it is time to go. Parents often have looks that tell their children that they need to behave.

Finally, presumed understanding can be very powerful. Similar experiences can really help speed up communication.

Overhead Partners Plus 2-5

Non-Verbal Communication and Culture Life Ways (Our Customs that Reflect Our Culture and Values)

- Reactions to silence
- Amount of space between bodies
- Eye contact
- Body postures
- Eyes that speak
- Presumed understanding that comes from similar experiences

Building Communication Skills continued

For example, when families of children with disabilities get together, it can be a relief for them to know that the person next to them knows how difficult it is to find good care for their children. It is helpful for caregivers to share with families the experiences that they have had working with children with special needs. This gives families a better idea of what they need to tell you and what you already know.

The following activity is designed to help participants talk more specifically about how communication facilitates the respite relationship.

Ask participants to turn to Section 2: "What You Need to Know About Communication" in their manuals. Introduce the first script.

We have talked about communication and how it works. Now, let's look at communication in action in respite.

There are several scripts laid out in this section. The first script is of a conversation between a family and a caregiver who are just getting to know each other.

Overhead Partners Plus 2-5

Non-Verbal Communication and Culture Life Ways (Our Customs that Reflect Our Culture and Values)

- Reactions to silence
- Amount of space between bodies
- Eye contact
- Body postures
- Eyes that speak
- Presumed understanding that comes from similar experiences

Building Communication Skills continued

Ask for two volunteers: one to read the Family part, and one to read the Caregiver part. When you have assigned roles, ask the participants to read the entire first script aloud.

Ask participants to talk about the kinds of communication at work in this script.

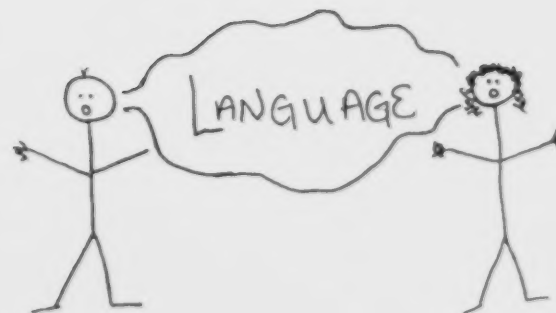
Participants will probably generate a lot of answers. It is particularly important to highlight the way that the family encouraged the caregiver to share more information about what she liked to do with children.

Move on to the next script on the next page.

What kinds of communication do we see used here? Verbal? Nonverbal?

What about the family. How did they encourage the caregiver to share more information? What language did they use?

This second script is a discussion that takes place during personalized training. The caregiver is learning about the child's feeding routine.



Building Communication Skills continued

Ask for more volunteers to read the roles in the second script. When they have done so, ask participants to share what they heard.

Again, there may be many answers. Here, highlight the way that the family perseveres, despite the caregiver's fears, and the words that the caregiver uses.

Move to the final script at the bottom of the page.

What did you hear going on in that script?

Notice how the family perseveres when the caregiver expressed fear in a negative way. These words were not intended to be hurtful, but they could have sounded hurtful to the family. But the family did not shut down, instead they continued to probe for additional information until the caregiver felt comfortable.

This final script is a conversation between a family and a caregiver after care has taken place. It is critical that families and caregivers continue to communicate throughout their relationships. This family has taken the time to check in with their caregiver after respite.



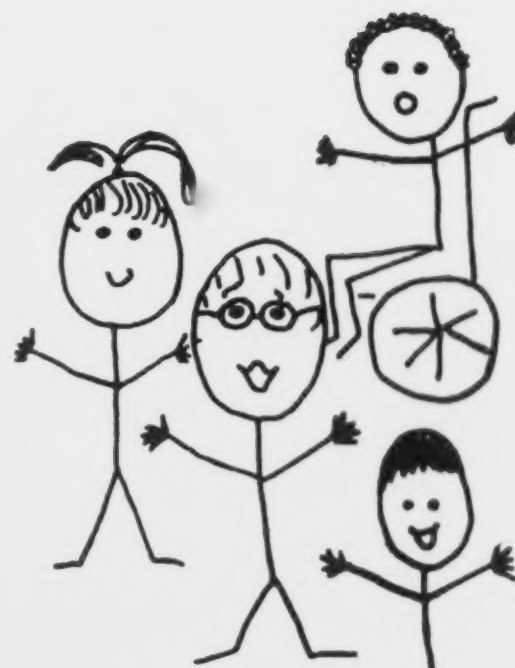
Building Communication Skills continued

Ask for two more volunteers to read through the script. After they have finished reading, ask for comments on communication.

Here, you want to make sure that participants recognize the need to check in after respite.

What did you hear going on in that script?

This is a great example of the need to check in after respite. This caregiver was open to sharing her experience, which is very helpful, too. Both the family and the caregiver use words to gather more information and to clarify what happened.



4
mins

Summary

Ask if there are any questions or comments about this section. Refer to overhead Partners Plus 2-6 Building Partnerships Through Communication. Refer participants to Section 2 in the Partners Plus **Family and Caregiver Manuals**.

Summarize the key points of the section.

Any questions on what we've covered so far?

As families and caregivers work together, they need to know how to communicate with one another. This communication will strengthen the partnership. Remember these simple points as you work together:

- Sharing thoughts and feelings helps you understand each other.
- It is as important to listen to each other as it is to talk to each other.
- Recognize and appreciate common experiences, similarities, and differences.
- Honesty and openness allow you to build cooperative, long-lasting relationships.

Overhead Partners Plus 2-6

Building Partnerships through Communication

- Sharing information increases understanding
- Listen carefully to each other!
- Share common experiences
- Appreciate differences
- Honesty and openness are key

**Section 2—Building Partnerships:
Communication
Suggested Overheads**

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Communication Is . . .

7 % Words

38 % Voice

55 % Facial and
Body Language



(UCLA, 1967)

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Partners Plus Workshop

Family and Caregiver Manuals Section 2

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PP 2-1

How Do You Feel?



Anxious



Angry



Bashful



Bored



Confident



Thinking



Scared



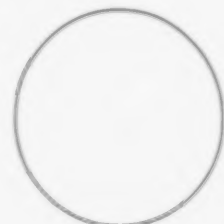
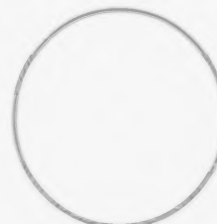
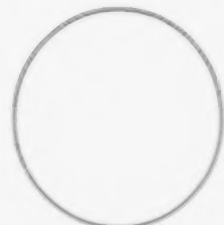
Innocent



Relieved



Confused



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PP 2-2

The Record



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PP 2-3

Six Messages of Communication

- What you **mean** to say
- What you **actually** say
- What the other person **hears**
- What the other person **thinks**
he or she hears
- What the other person **says**
- What you **think** the other
person says

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Nonverbal Communication and Life Ways

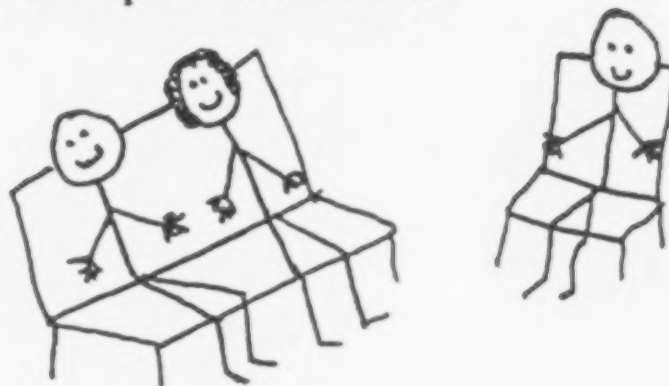
- Reactions to silence
- Amount of space between bodies
- Eye contact
- Body postures
- Expressive eyes
- Presumed understanding that comes from similar experiences

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Building Partnerships through Communication

- Share information to increase understanding
- Listen carefully to each other
- Share common experiences
- Appreciate differences
- Be open and honest



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Family and Caregiver Manuals Section 2

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PP 2-6

45
mins

Section 3—Building Partnerships: Families and Caregivers Working Together

Section Purpose

- To give participants an overview of and introduction to building successful relationships with each other.

Objectives for Families

- Become more aware of caregivers' perspectives
- Understand why many caregivers experience "burn out" and stop providing respite care
- Know strategies to prevent caregiver burn out

Objectives for Caregivers

- Become more aware of families' perspectives
- Recognize families' need for respite and the value of the service that respite caregivers provide
- Understand the importance of learning about a family's experience from that family

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 3, "Building Partnerships: Working Together," in the Partners Plus **Family and Caregiver Manuals**.

Read each family story so that you feel comfortable reading any of them aloud word for word.

Select a training option to discuss family stories. Be prepared to either facilitate discussion, share personal experiences, or discuss "A Personal Story," outlined in Section 3 of the **Family and Caregiver Manuals**.

Prepare overhead transparencies of:

- Overhead Partners Plus The Challenges of Respite 3-1
- Overhead Partners Plus Meeting the Challenge 3-2
- Overhead Partners Plus Successful Partnerships 3-3

Preparing for Training continued

Note to Trainers

Often during workshops, participants meet objectives for this section in previous sections. If so, make appropriate modifications in your presentation.

Corresponding Sections

Please refer participants to Section 3, "Building Partnerships: Working Together" in the Partners Plus **Family and Caregiver Manual**.

Notes about Presenters

The first part of this section deals specifically with building relationships with families who have children with special needs. As a result, we strongly recommend that a trainer with personal experience as a family member facilitate or co-facilitate this session. Depending on their comfort level, family members can provide a different perspective through personal stories and anecdotes.

Similarly, the second part of this section deals with building relationships with caregivers. We suggest that a trainer who has experience as a caregiver for children with special needs facilitate or co-facilitate this session. Again, trainers with any kind of

experience working with children with special needs can add to the training by sharing their experiences if they are comfortable doing so. Family members who have worked with respite caregivers can also provide valuable insight as trainers in this part of the section.

During this section, participants may have information to share. Group sharing can be unpredictable and challenging to facilitate. However, families and caregivers who participated in the field testing of this model consistently said the stories they heard in this group discussion provided some of the most valuable information that they learned.

We strongly suggest that you take the time to allow participants to share during this section. Extra time is built into the agenda to allow you to do that.

If you must curtail discussion in the interest of time, use positive language, such as: "I hope our discussion can continue during a break in the training, but unfortunately, we need to move on in order to address all of the information and stay on schedule. Thank you for sharing your experiences with us."

5
mins

Introduction to Sharing Perspectives

Introduce this section by talking about how understanding helps families and caregivers build lasting relationships with each other.

We have talked about communication, which we feel is one cornerstone of a strong respite relationship. Understanding is another cornerstone that grows only out of communication.

People who understand each other's perspectives can interact more respectfully and sensitively. In respite, once you match up with caregivers and families, it is important that you spend time sharing perspectives, and talking honestly about how the relationship is working for you. In this section, we will share stories from families and caregivers about what it is like to be in their shoes.

As we talk, we hope that you will feel free to add your perspective. We may say things that ring true with you, and other things that are different from your experience. Everyone has slightly different experiences. We will start with family perspectives and move on to caregiver perspectives later.

There are no overheads for this section.



20
mins

Family Perspectives

"Welcome to Holland"

As an introduction to family perspectives, read this story to participants exactly as it is written. This story is one family's perspective, and the message must be delivered as intended by that family.

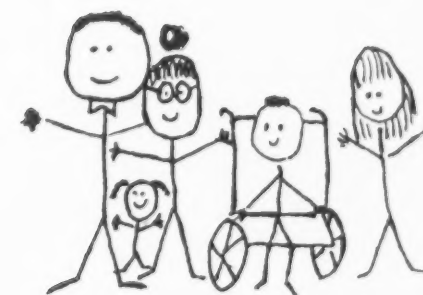
In order to give the most powerful representation of this family's experience, read expressively with sincere emotion for their concerns.

Participants may want to follow along in Section 3 of the Partners Plus **Family** and **Caregiver Manuals**.

I would like to read you a story written by the parent of a child with Down Syndrome. It expresses one parent's view of what it is like to have a child born with special needs. The story is called "Welcome to Holland."

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . .

There are no overheads for this section.



Family Perspectives continued

Read "Welcome to Holland" for the group.

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans—the Coliseum, the Michelangelo's David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes in and says, "Welcome to Holland!"

"Holland!?!!" you say. "What do you mean, 'Holland'? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy!" But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people that you would have never met.

179

175

Family Perspectives continued

Read "Welcome to Holland" for the group.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for awhile you look around and you begin to notice Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned." The pain of that will never, ever, go away because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't go to Italy, you may never be free to enjoy the very special, the very lovely things in Holland.

(Emily Perl Kingsley, 1981)



Family Perspectives continued

Summarize the key messages of the story in your own words.

Few families plan for or expect to have a child with special needs. To develop a partnership with that family, caregivers should think about what that experience might be like.

In this story, Ms. Kingsley, shares her thoughts and feelings about learning that she was the parent of a child with special needs. She talks about the huge impact that child's disability had on her life and other family members. She talks about the pain that will never go away that came because of her child's special need.

But Ms. Kingsley also tells us that her child is special, not just in his special needs but also in the joy he brings. It is important to remember that there are joys and triumphs in raising and loving a child with special needs.



Family Perspectives continued

Note to the Family Presenter:

There are several different ways to meet the objectives of this section: either by asking the group to share experiences, or by sharing your own experiences, or by following the discussion outlined in Section 3 of the Partners Plus **Family and Caregiver Manuals**. Choose the method most comfortable for you.

If you select Options 1 or 2 (below), you may find that it takes less than 20 minutes. Remind participants that they can continue sharing information during a break or after training. If you select Option 1 or 2 and after you have completed the discussion, proceed to page 3.14 of the **Trainer's Workshop Manual** to continue with trainer notes, content, and section objectives.

If Option 1: Sharing Group Reactions

Invite families to share their reactions to this story with the group.

There are a number of families here who I'm sure can relate to this story. Would anyone like to share their personal experience with caring for a child with special needs? What memories or feelings did this story raise for you?

There are no overheads for this section.

Family Perspectives continued

If Option 2: Sharing Personal Experiences

This is a good time for family presenters to share related personal stories if they wish to do so.

I can really relate to this story. I have a personal history of caring for a child with special needs . . .

There are no overheads for this section.

If Option 3: Following Section Discussion

Refer participants to "A Personal Story" in Section 3 of the Partners Plus Family and Caregiver Manuals.

Give participants some time to read through the story.

Now let's take a few moments to read the story by Ms. Moore to ourselves. Once everyone has finished we can share our reactions.



Family Perspectives continued

If Option 3 (continued): Following Section Discussion

Follow the discussion outlined at right.

Ms. Moore touches on a lot of important topics in her story. She begins by talking about the impact Matthew's birth had on her family. Like Ms. Kingsley's family, her family lived a very different kind of life when her child was born. Matthew required round-the-clock care, and certainly his birth changed their life. Even children who require less intense care affect families. Sometimes, families no longer feel comfortable in the communities where they live.

People who do not take the time to learn about children and their special needs sometimes react in ways that are hurtful to the child and the family. Sometimes, people stare or ask insensitive questions or say insensitive things. Sometimes, close friends of the family are so unsure of what to say they never come by to say anything at all.

There are no overheads for this section.



Family Perspectives continued

If Option 3 (continued): Following Section Discussion

Follow the discussion outlined at right.

Ms. Moore goes on to describe more about the impact Matthew had on her family. She talks about what they learned from Matthew. Often, people in the community only see the negative side to raising a child with a special need. The reality is that there are hard times. However, families tell us that there are many positive sides to raising their children too. Matthew taught Ms. Moore's family a lot about their talents as well. They learned that there were people in their community who would support them.

Other people in Ms. Moore's community were blinded by Matthew's disability. They could not, or would not, see the child behind the diagnosis. One of the most important things that we share with you today is this: all children have special gifts and special needs. When you are working with children with special needs, remember to look for the children's strengths. Your respite relationship will be made stronger!

There are no overheads for this section.



Family Perspectives continued

If Option 3 (continued): Following Section Discussion

Follow the discussion outlined at right.

Ms. Moore also talks about the professionals who worked with her family and Matthew. Very often, families with children with special needs have many people coming in and out of their homes. The services that these professionals provide can be very helpful to families and children. Often, their work is valued highly by families. However, it is difficult to have so many people in their homes. Their lives are less private. Needing help to learn how to care for their children can make parents feel inadequate at times. Caregivers can be sensitive to those issues.

Ms. Moore also talks about her family's goals for Matthew. Her family wanted two things for her son. All families have dreams for their children. Ms. Moore's goals for Matthew are not so different from the goals other families have for their children. In working with families, it might be important for caregivers to take some time to

There are no overheads for this section.



Family Perspectives continued

If Option 3 (continued): Following Section Discussion

Follow the discussion outlined at right.

learn the goals that families have for children. Listen to what families are doing to help children toward their goals. Caregivers might also have some ideas about how to help them reach their goals.

Ms. Moore closes by talking about respite and what it meant to her family. The respite care that Ms. Moore received was important to her whole family. As we said earlier, families need time to relax, recuperate, focus on other things, and maintain other relationships.

Ask for input from the group.

Would any of the families in the room like to share what respite might mean for their family?

There are no overheads for this section.

Family Perspectives continued

Following Section Discussion

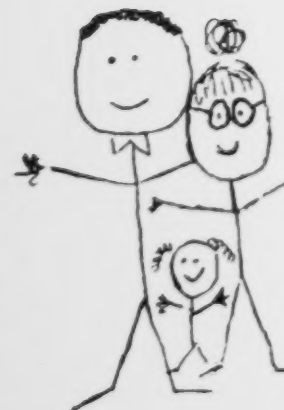
Continue this discussion by talking about the stresses of raising children.

Throughout this chapter in the manual, there are stories written by family members. The stories are about children with a range of ages and special needs. I encourage you to take the time to read through these perspectives later as they will give you a deeper understanding of families, and how important respite can be.

Raising any child can be challenging. Research tells us that changes in families' lives pose the greatest challenge. Families of children with special needs face the same worries and concerns as other parents.

Children with special needs may need additional support. Some children with special needs require extra help with everyday tasks like eating, moving from place to place, or communicating. In addition, when families of children with special needs are making larger life changes, their choices may be more limited. For example, when they select schools for their children, they need to consider a whole list of service providers in addition to a teacher.

There are no overheads for this section.



Family Perspectives continued

Following Section Discussion

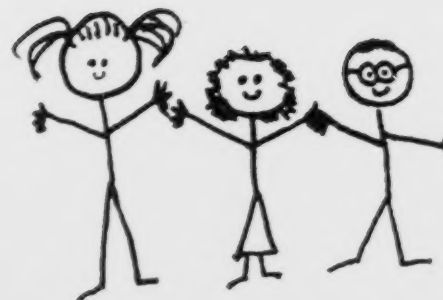
Continue this discussion by talking about the stresses of raising children.

It is not surprising that these families experience more stress than families with typically developing children. The key to dealing with stress depends on how you perceive a situation. The same situation can be stressful to one person but not stressful for another.

If you perceive a situation as stressful, you can reduce your stress by using a variety of coping strategies.

Respite can provide stress relief alone. It also gives families the opportunity to do some of these activities that relieve stress.

There are no overheads for this section.



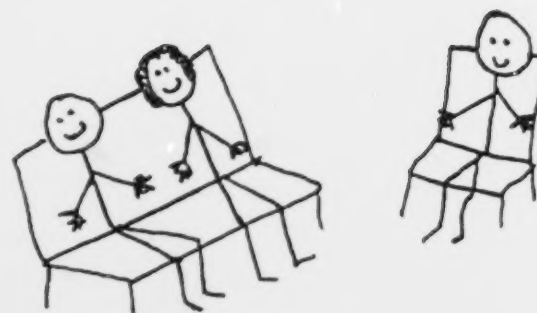
Family Perspectives continued

Following Section Discussion

Refer participants to "Strategies for Dealing with Stress" in Section 3 of the Partners Plus Family and Caregiver Manuals.

It is important to remember that caregiving can be stressful for caregivers as well. We encourage families to share information with caregivers about how to work with their children. We also encourage open communication. Talk with caregivers about how they deal with stress. Can you help them relieve the stress they may have when caregiving?

There are no overheads for this section.



8
mins

Challenges of Respite

Introduce the concepts of this section.

Refer to overhead Partners Plus The Challenges of Respite 3-1. Participants may wish to follow along on in Section 3 in the Partners Plus **Family** and **Caregiver Manuals**.

When the Partners Plus model was first developed, families said that they had trouble keeping caregivers.

Caregivers gave these reasons for stopping respite care:

- Respite is harder than they expected. As families are training their caregivers, we encourage you to be honest with them. Tell caregivers the challenges of working with your children as well as the joys.
- Time or physical demands are too great. Caregivers can dedicate too much of their time and energy to respite. Too much, too fast, can lead to caregiver burnout. Families and caregivers need to spend time talking realistically about the caregivers' schedules.

Overhead Partners Plus 3-1

The Challenges of Respite

Caregivers may stop giving respite if:

- Respite is harder than they expected
- Time demands or physical demands are too great
- They don't feel appreciated
- Training is not adequate
- "Burn out" occurs

Challenges of Respite continued

Explore the reasons why caregivers may stop giving respite care.

- Caregivers also need to be adequately trained. They need to have the skills to give the care children need. Without this training, caregivers will be uncomfortable and feel stressed. Later in this training we will talk more with families and caregivers about personalized training.
- Sometimes, caregivers' patience just wears out. If caregivers seem stressed, families must take the time to find out why and how they can help.
- Finally, caregivers leave if they don't feel appreciated. Families can show their appreciation for caregivers in a variety of ways.

Some strategies are listed in Section 3 of the **Family Manual**.

Overhead Partners Plus 3-1

The Challenges of Respite

Caregivers may stop giving respite if:

- Respite is harder than they expected
- Time demands or physical demands are too great
- They don't feel appreciated
- Training is not adequate
- "Burn out" occurs

7 mins

Meeting the Challenge

Refer to overhead Partners Plus Meeting the Challenge 3-2. Participants can follow along in Section 3 in the Partners Plus Family and Caregiver Manuals.

Families and caregivers can work together to maintain their relationships. Caregivers can learn families' purpose for respite. This gives them a sense of how much their work is needed and valued.

Caregivers can be active in developing personalized training plans. In this way, they can make sure that they get all of the information they need to feel comfortable.

Be clear about your terms for providing respite. Take the time to consider your schedule. Overcommitting leads to burnout.

Learn more about working with children and families. Today, we will give caregivers information to use while providing respite care. We encourage caregivers to continue collecting information that will be helpful to them in their work.

Overhead Partners Plus 3-2

Meeting the Challenge

- Understand the purpose for respite
- Be active in helping to develop training!
- Be clear about your terms
- Learn about working with children and families
- Get information and support from other caregivers

Meeting the Challenge continued

Explore ways to help caregivers better provide respite care.

Also, make the most of your personalized training time. Get to know the families and children you will be working with. As we said earlier, understanding is a powerful tool.

Finally, get information and support from other caregivers. It is helpful to have someone who you can discuss problems and share ideas with!

Overhead Partners Plus 3-2

Meeting the Challenge

- Understand the purpose for respite
- Be active in helping to develop training!
- Be clear about your terms
- Learn about working with children and families
- Get information and support from other caregivers

5
mins

Summary

Ask if there are any questions or comments about this section.

Conclude the section by restating the key points.

Refer to overhead Partners Plus Successful Family and Caregiver Partnerships 3-3. Refer participants to Section 3 in the Partners Plus Family and Caregiver Manuals.

Does anyone have any questions or comments at this stage?

Families and caregivers can build successful respite relationships that grow into long-lasting partnerships. Use understanding and communication and these guidelines will become second nature in time:

- Appreciate differences.
- Be willing to learn from each other.
- Call on each other for help.
- Allow time to talk and share experiences.
- Finally, share a commitment to a child.

Overhead Partners Plus 3-3

Successful Partnerships

Successful partnerships are those in which families and caregivers:

- Appreciate differences
- Are willing to learn from each other
- Ask each other for help
- Allow time to talk and share experiences
- Share commitment to children

**Section 3—Building Partnerships: Families
and Caregivers Working Together
Suggested Overheads**

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213

The Challenges of Respite

Caregivers may stop giving respite if:

- respite is harder than they expected
- time demands or physical demands are too great
- they don't feel appreciated
- training is not adequate
- "burn out" occurs

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214



Partners Plus Workshop

Family and Caregiver Manuals Section 3

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 3-1

Meeting the Challenge

- Understand the purpose for respite
- Be active in helping develop training
- Be clear about your terms
- Learn about working with children and families
- Get information and support from other caregivers

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Partners Plus Workshop
Family and Caregiver Manuals Section 3
Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 3-2

Successful Partnerships

**are those in which families
and caregivers:**

- appreciate differences
- are willing to learn from each other
- ask each other for help
- allow time to talk and share experiences
- share commitment to children

DRAFT 10.99



**Partners Plus Workshop
Family and Caregiver Manuals Section 3
Child Development Resources, P.O. Box 280, Norge, Virginia 23127**

PP 3-3

Section 4—All Kids Like Cookies

Objectives

- Experience firsthand some of the challenges faced by children with special needs, and
- Identify the ways in which children with special needs adapt to their environments

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 4, "All Kids Like Cookies," of the **Family and Caregiver Manuals**.

Prepare for the All Kids Like Cookies Activity, Parts 1 and 2. While it requires advance preparation, the All Kids Like Cookies Activity vividly demonstrates the difficulties that children with disabilities can experience. Families and caregivers who participated in the field testing of this curriculum overwhelmingly concluded that this was one of the best and most memorable training activities in which they had ever participated.

Determine the number of participants. Prepare enough materials for the group so that half will receive handout number 1, and the rest will receive handout number 2.

1. All Kids Like Cookies Handout
Partners Plus Supplement 1-E (easy version)
2. All Kids Like Cookies Handout
Partners Plus Supplement 1-H (hard version)

Prepare four stations for the All Kids Like Cookies Activity, Part 2. Gather the following materials for each station:

Station 1: Vision

- Directions (Photocopy the Partners Plus Supplement 2: Directions for Stations for All Kids Like Cookies Activity, Part 2)
- A table and a few chairs
- Safety glasses (available at hardware stores). Wrap the lenses of one pair in foil with a pinhole in each lens. Wrap the lenses of the second pair in several layers of saran wrap. Wrap the lenses of the third pair in wax paper.

Preparing for Training continued

Station 1: Vision (continued)

- Blindfolds
- Crayons
- Several children's books and magazines
- A cup
- A pitcher with water

Station 2: Speech

- Directions (Photocopy the Partners Plus Supplement 2: Directions for Stations for All Kids Like Cookies Activity, Part 2)
- A table and a few chairs
- A bag of marshmallows
- A package of gauze
- Paper towels or napkins
- A trash can

Station 3: Fine Motor

- Directions (Photocopy the Partners Plus Supplement 2: Directions for Stations for All Kids Like Cookies Activity, Part 2)

- A table and a few chairs
- Several pairs of thick gloves (gardening or work gloves)
- Masking tape
- Two puzzles for young children with big pieces and knobs
- Large beads or pasta that can be threaded onto a string
- Thick string to thread the beads or macaroni with holes
- Two or three small, manipulative toys, like a wind up truck

Station 4: Gross Motor

- Directions (Photocopy the Partners Plus Supplement 2: Directions for Stations for All Kids Like Cookies Activity, Part 2)
- 10 to 15 feet of cleared space where participants can walk
- Two large balls. Place the balls at one end of the walkway.
- Three-foot long pieces of thick string
- Kick-ball, large toy (stuffed animal or doll)
- Video tape

Prepare overhead transparencies of:

- Overhead Partners Plus All Kids Like Cookies 4-1

2
mins

Introduction to All Kids Like Cookies

Introduce the section. The purpose of this section is for trainers to help participants understand some of the challenges for children with special needs, and how caregivers can help children with special needs in both their daily activities and group care settings.

Refer to overhead Partners Plus All Kids Like Cookies 4-1.

Section 4: All Kids Like Cookies, was adapted from:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *SpecialCare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.

In the last section, we spent time talking about the perspectives of families and caregivers. Children are the third members of respite relationships. "All Kids Like Cookies" is an activity designed to give you the opportunity to experience the challenges that children with special needs face.

Before we begin this activity, let's read this message from the Council for Exceptional Children that sums up why this activity is important for families and caregivers alike:

"We cannot help until we understand.
We cannot understand until we feel.
We cannot feel until we become."

Overhead Partners Plus 4-1

All Kids Like Cookies

"We cannot help until we understand.
We cannot understand until we feel.
We cannot feel until we become."
—Council for Exceptional Children

20
mins

All Kids Like Cookies Activity

Set the tone for the activity.

This activity is divided into two parts, and is a little more challenging than some of the others we've tried. The first part of the activity is done individually. You'll take an XYZ test. During this test, I cannot allow any talking and all eyes must stay on your own paper.

There are no overheads for this section.

Distribute the XYZ Test alternately, giving half the participants the "easy" version and half the "hard" version. Use Partners Plus Supplementary Material PP 4 SM. Do not let the group know that you are distributing two different tests.

Do not turn over your papers until I tell you to, and remember, do not talk or ask questions.

Place the handouts face down in front of the participants. Do not allow any talking during this time.

Each of you has received a test. There are 16 items on the test. When you finish the test, put your pencil down and turn your paper over. You will have three minutes to complete the test. Begin.



All Kids Like Cookies continued

Time participants for three minutes.
Announce when time is up.

Have participants grade their own tests.

Again, do not allow questions or talking at this stage. Later, when you discuss the activity, participants will have an opportunity to discuss what they experienced during the test.

(The test was adapted from the Early Integration Training Project, 1991.)

Do not start a discussion.

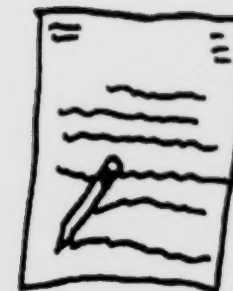
Time is up, put your pencils down.

That wasn't so hard, right? I'll call out the correct answers and each of you can score your work.

- | | |
|------|-------|
| 1. D | 9. D |
| 2. C | 10. C |
| 3. A | 11. C |
| 4. C | 12. D |
| 5. C | 13. A |
| 6. D | 14. D |
| 7. D | 15. B |
| 8. A | 16. D |

How'd you do? Raise you hand if you got all 16 answers correct; 10 or more answers correct; 5 or more answers correct; fewer than 5 answers correct. We'll have an opportunity to discuss the test after the next activity.

There are no overheads for this section.



All Kids Like Cookies continued

Divide the participants into four equal groups. Use creative ways to divide the group, such as four different kinds of candy, gum, color pencils, etc.

Explain Part 2 of the "All Kids Like Cookies" activity.

Begin timing the first rotation of stations. Circulate among the groups to make sure that everyone understands what to do and has enough time to try all the activities.

After 4 minutes, give a signal and have each group move to another station. Continue rotating until all of the groups have visited all four stations.

You will work in small groups for Part 2. We're going to form small groups now . . .

In a minute, we will ask you to go to an assigned station to begin Part 2 of the "All Kids Like Cookies" activity. Directions are provided at each station. Read and follow the instructions at each of the four activity stations.

You will have about 4 minutes at each station. At our signal, move to the next station.

After you have had a chance to visit all four stations, we will regroup to talk about what you experienced. Begin.

There are no overheads for this section.



8
mins

Discussion

Debrief both Part 1 and Part 2 of the "All Kids Like Cookies" activity.

Talk about the individual activity and then the small groups activities.

Allow a minute for participants to examine and react to the differences in their tests.

Okay! Let's gather together and talk about what we just experienced.

Let's start with the test. What were you thinking during the test? How did it make you feel? How about for those of you who did not do as well as you expected—how did you feel? Did anyone just give up?

Half the group was given a significantly harder test than the other half. Take a minute to look at the test of the person next to you.

Children with various disabilities affecting the way they think or solve problems often have trouble in school. They can feel frustrated and incompetent. Many children with these disabilities give up in school and need encouragement and support to continue.

There are no overheads for this section.



All Kids Like Cookies continued

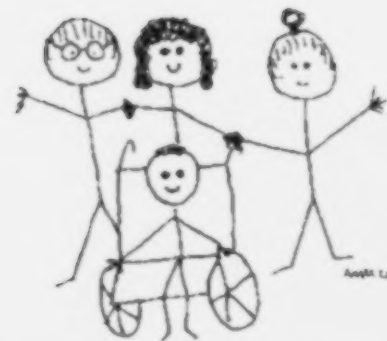
We know that children with mental retardation do learn. It may be at a different level or rate than others. They may need more repetition to remember information.

Children with learning disabilities have differences in how they learn. They may need to take tests orally. A variety of teaching techniques are used to teach all children. For example: some children learn basic math by feeling the shape of numbers made out of sandpaper or felt, other children may need to sort out objects to learn math ideas.

Move on to Part 2. Discuss how each station posed challenges for the group.

Let's talk about Part 2: the stations. At station 1, you were given activities that were done with a visual impairment. Were you able to see anything at all? How did you accomplish the activities? Did you have to modify your behavior in order to accomplish each task?

There are no overheads for this section.



All Kids Like Cookies continued

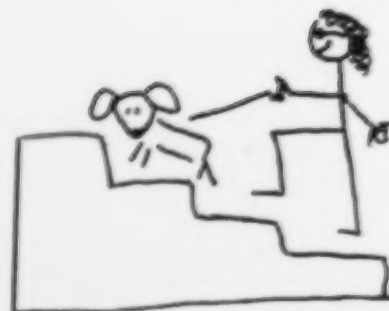
If participants do not offer enough illustrations for adopting the station activities, the trainer should give them.

Children with visual impairments often hold their heads at an unusual angle to keep points of interest in their vision. Were all the tasks at the vision station appropriate for children with visual impairments? How might they have been adapted?

How about using plain paper with scented markers, rather than paper with pictures and lines to stay in? What about using large print books and magazines?

Remember, you may have to think about adapting activities for children with special needs. Use activity materials that are enjoyable enough through smell or feel, such as cooking or clay molding. Make sure activities give children a sense of accomplishment through a balance of challenge and success. Adapted activities are often fun for all children!

There are no overheads for this section.



All Kids Like Cookies continued

Discuss how station 2 posed challenges for the group.

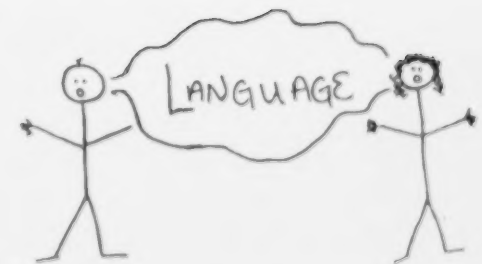
Think about the speech activities at station 2. What was this experience like for you? How did you make yourselves understood?

In this activity many of you chose to keep your messages brief. Children with speech impairments often become frustrated when others do not understand them and will say as little as possible. It is easy to misinterpret silence as not having anything to say.

Did anyone use gestures? Children with speech impairments often use other parts of their bodies to communicate. One illustration of this is when a child with no speech and limited control of their body movements, uses his or her eyes intently to communicate.

Experiencing the activities at the speech and language station often makes us laugh at ourselves and others. Children with speech impairments do not laugh at the differences in the way they sound. Sometimes they stop talking rather than cope with the difficulty of getting people to understand them.

There are no overheads for this section.



All Kids Like Cookies continued

Discuss how station 3 posed challenges for the group.

In group care settings, children may ask about another child whose speech is different, "why does she talk funny?" Caregivers should model responses that are matter of fact and appropriate to a child's level of understanding. One response may be, "you are having trouble understanding Anna." Caregivers can also teach children specific ways to communicate that increase understanding and promote social interactions.

Next, let us talk about the fine motor activities at station 3. Did you feel awkward performing the group tasks with limited use of your fingers and hands? How did you adapt to accomplish the tasks? Were all the activities appropriate?

In order for children to fully participate and learn about the things in their environment they need to handle objects. A child with fine motor impairment may need to have a knob glued to puzzle pieces. When an older child's ability to solve complex puzzles is affected by fine motor impairments adaptations are needed.

At station 3, some of you may have been too frustrated to have enjoyed stringing objects because the holes were too small and the string too limp. An appropriately planned activity would have included objects with larger holes and stiffer string.

There are no overheads for this section.



All Kids Like Cookies continued

Discuss how station 4 posed challenges for the group.

At station 4, the tasks you did require using the large muscles of your body. What was your experience during this activity? How did you adapt?

Children with motor impairments that affect their legs, feet, and arms may look different when they move their bodies. During the activity at station 4, participants often remain in an upright position while walking toward the toys. Sometimes participants will roll on the floor or move on their knees to get to the toys.

A child with motor impairments affecting their large muscles, may need to use more energy and effort to get around. Some children may use special equipment to help them, such as walkers and wheelchairs. Clear pathways are important to mobility. Generally, eliminating physical barriers that limit children's participation is as simple as rearranging furnishings or play areas.

There are no overheads for this section.



5
mins

Summary

Conclude the section by summarizing key points.

Are there any other questions or comments you'd like to add about All Kids Like Cookies?

There are no overheads for this section.

Today, we have had the opportunity to peer inside the lives of children with special needs. We must remember, however, that the disabilities we experienced were temporary. Children with special needs and their families deal with these challenges on a daily basis. During the activities in ALL KIDS some of you looked different in the ways you moved your bodies, used your voices, or behaved.

It may be necessary for caregivers in group settings to help children feel comfortable with the way we look, sound, or behave when involved in the same activities. Caregivers can model accepting attitudes that celebrate differences.



All Kids Like Cookies continued

Sometimes directors and staff of recreational programs think that they will have to make extensive changes to include children with disabilities. Often, they only need to make a few accommodations to meet the needs of children with special needs. Valuable respite to families who have children with disabilities can be offered by providing the same kinds of appropriate experiences that characterize quality programs for all children. Leaders, directors, and counselors of community children's and youth programs can provide valuable respite to families who have children with disabilities.

There are no overheads for this section.

It is important to note how children adapt to what is asked of them. While many of you were frustrated with the activities today, you managed to accomplish what we asked you to do. Children with special needs have incredible strengths. As you work with them, notice their strengths and build on them.

If One Day Workshop:

The end of this session provides a natural breaking point for a one-day workshop. If you are presenting a full day workshop, we recommend breaking for lunch after this activity.

At this point, we're going to take a break for lunch. We'll meet back here at ...

Section 4—All Kids Like Cookies

Suggested Overheads

DRAFT 10.99

All Kids Like Cookies

"We cannot help until we understand.

We cannot understand until we feel.

We cannot feel until we become."

— Council for Exceptional Children



DRAFT 10.99



Partners Plus Workshop

Family and Caregiver Manuals Section 4

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 4-1

Section 4—All Kids Like Cookies Supplemental Materials

DRAFT 10.99

All Kids Like Cookies Activity

Part 1: XYZ Test



Directions: Circle the best answer for each question.

1. The following is a color:
 - a. fish
 - b. car
 - c. stove
 - d. blue
2. $6 \times 2 =$
 - a. 27
 - b. 97
 - c. 12
 - d. 67
3. How many inches are in a foot:
 - a. 12
 - b. 3
 - c. 36
 - d. 18
4. The following is not a planet:
 - a. Mars
 - b. Jupiter
 - c. Hamilton
 - d. Saturn
5. When riding a bicycle at night, you should
 - a. wear dark clothing and sunglasses.
 - b. ride on the other side of the road, opposite the side for day riding.
 - c. wear a white shirt or coat, and turn on head lamp and tail lamp.
 - d. not ride at night.
6. The following state is not located in the East:
 - a. Maine
 - b. Florida
 - c. Virginia
 - d. California
7. A refrigerator is used to
 - a. wash clothes.
 - b. cook food.
 - c. cut food.
 - d. cool food.
8. The following is a bird:
 - a. robin
 - b. deer
 - c. cat
 - d. monkey
9. The following is not a form of transportation:
 - a. bus
 - b. train
 - c. automobile
 - d. football
10. The following is a winter month:
 - a. May
 - b. July
 - c. December
 - d. September

11. The following is an even number:

- a. 1
- b. 11
- c. 6
- d. 15

12. A dentist would

- a. deliver a baby.
- b. prescribe glasses.
- c. perform a heart transplant.
- d. pull a tooth.

13. Milk could be purchased at

- a. a grocery store.
- b. a hardware store.
- c. a florist.
- d. a clothing store.

14. The following would be used to mend clothes:

- a. a nail
- b. a staple
- c. a tack
- d. thread

15. The following would be worn for snow skiing:

- a. wing tips
- b. boots
- c. sneakers
- d. sandals

16. The following is used to brush teeth:

- a. a shovel
- b. a hose
- c. a wrench
- d. a brush

Adapted from:

Anketell, M., Dunn, L., and Sykes, D. (Eds.). (1991). Activity 6: IQ test. In The early integration training project trainer's manual. Columbus, OH: Ohio State University, Center for Special Needs Population.

All Kids Like Cookies Activity

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 - b. ride on the other side of the road, opposite the side for day riding.
 - c. wear a white shirt or coat, and turn on head lamp and tail lamp.
 - d. not ride at night.
6. The term Dorian refers to
 - a. a Greek column style.
 - b. a shade of gray.
 - c. a psychoanalytic procedure.
 - d. a musical style prevalent in the Middle Ages.
7. A chain has 5 links. The first link can hold 7 pounds. The second can hold 9 pounds. The third can hold 4 pounds. The fourth can hold 8 pounds. The last can hold 7 pounds. How many pounds can the whole chain hold?
 - a. 9 pounds
 - b. 7 pounds
 - c. 8 pounds
 - d. 4 pounds
 - e. 35 pounds
8. The henry is
 - a. a unit of measurement of inductance.
 - b. a unit of resistance.
 - c. a volt equivalent.
 - d. a chemical substance.
9. Alnico is
 - a. a skin disease.
 - b. a type of mental illness.
 - c. an engineering term.
 - d. a precious metal.
 - e. an alloy used for magnets.

10. The term joule refers to
- a. a musical instrument.
 - b. tempo.
 - c. a unit of energy.
 - d. a carpenter's tool.
 - e. a type of electrical wire.

11. Kirchoff is well known for his contributions to the field of
- a. music.
 - b. psychology.
 - c. electronics.
 - d. economics.
 - e. education.

12. A French seam is
- a. a machine stitch.
 - b. a seam within a seam.
 - c. a type of wood lamination.
 - d. a seam sewn with a double needle.

13. Muntin is used in
- a. The production of a window frame.
 - b. food production (cooking).
 - c. farming.
 - d. tuning a piano.

14. The term puzzolano refers to
- a. music tempo.
 - b. a difficult problem.
 - c. a food ingredient.
 - d. volcanic dust.

15. A darty is
- a. a kitchen design.
 - b. a flat tool used in plastering.
 - c. a type of saw.
 - d. a type of linen.
 - e. a fishing lure.

16. The word penatonic refers to
- a. five states of emotional behavior.
 - b. five types of antidepressant medicine.
 - c. a play by Sophocles.
 - d. a five-tone scale of music.

Adapted from:

Anketell, M., Dunn, L., and Sykes, D. (Eds.). (1991). Activity 6: IQ test. In The early integration training project trainer's manual. Columbus, OH: Ohio State University, Center for Special Needs Population.

All Kids Like Cookies Activity

Directions for Station #1—Vision

Put on a pair of special glasses or blindfold and try to do the following activities. Take turns using different pairs of glasses.

1. Color a picture and try to stay in the lines.
2. Look at the book.
3. Pour a cup of water.
4. Complete the crossword puzzle.

All Kids Like Cookies Activity

Directions for Station #2—Speech

1. Have one person play the role of the child.
2. The child puts 2-3 marshmallows or some gauze in his/her mouth, on his/her tongue.
3. The child asks other group members a question, or asks them to get something.
4. Switch roles so that everybody has the chance to be the child.

All Kids Like Cookies Activity

Directions for Station #3—Fine Motor

Put on a pair of gloves or tape your fingers together. Try to do the following activities.

1. Put a puzzle together.
2. String beads.
3. Play with a toy.
4. Take off and put back on your watch, earrings, bracelet, etc.

All Kids Like Cookies Activity

Directions for Station #4—Gross Motor

1. Put a ball between your ankles.
2. Clasp your hands and keep them together during the activity.
3. Use any method (except hopping) to reach the toy.
4. With hands still clasped, pick up the toy or video and give it to another group member.

5
mins

Introduction to Separate Family and Caregiver Sessions

Begin by explaining what families and caregivers will be doing.

During the next several sections, families and caregivers will be learning different things. Families will be learning more about finding, screening, interviewing and training caregivers for their children. Caregivers will be learning about special needs, child development, common disabilities, health needs, and becoming Partners caregivers.

There are no overheads for this section.

Identify which trainer will work with each group and where they will meet.

Families and caregivers will work as separate groups with a trainer who will cover specific topics in your manuals. At the end of the these separate sessions, you will reunite for a final activity and some closing thoughts.

Any questions?

258

259

20
mins

Section 5 Families—Finding Respite Caregivers

Objectives

- Develop strategies for finding appropriate respite caregivers
- List qualities/criteria for selecting caregivers
- Identify potential caregivers in their natural support networks
- Know other strategies for finding respite caregivers

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 5, "Finding Respite Caregivers," in the **Family Manual**.

In this section, families get information on matching with caregivers through the Partners program. Each community decides how or if they distribute information on trained caregivers to families in the community. Please prepare for this section by becoming familiar with these procedures and developing necessary materials to communicate them to families.

Families in training often are a great resource for one another. This section includes extra time to allow for discussion and information sharing.

Overheads are not necessary for Section 5 in the Family Break-Out Session. If you prefer, you may create overheads for your own use.

Corresponding Sections

Please refer participants to Section 5, "Finding Respite Caregivers," in the **Family Manual**.

2
mins

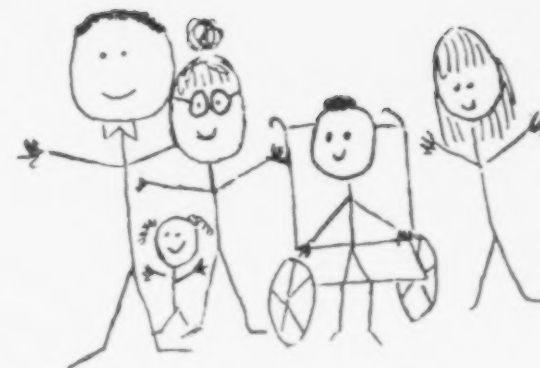
Introduction

Introduce this section.

Families need to think ahead when they are finding and training caregivers. In order to make sure that everyone in the partnership is comfortable, families and caregivers must commit time and energy. This means that you want to start looking for a respite caregiver NOW, before you reach a point where respite is an emergency need.

The Partners model is based on the idea that families want to find and train their own caregivers. It can be difficult to find appropriate people to care for your children. Today, we will give you a few strategies to help you find caregivers who will be helpful to you.

There are no overheads for this section.



5
mins

Important Qualities for Your Respite Caregiver

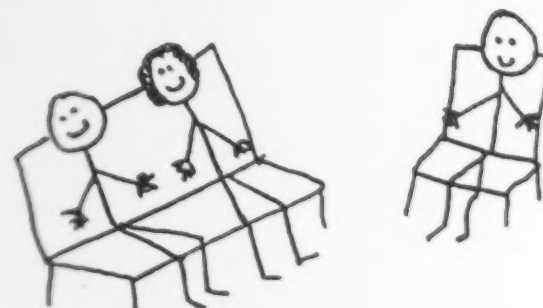
Introduce this section.

Before you begin looking for a caregiver, it is helpful to think about what qualities you feel are important in a caregiver for your child.

There are no overheads for this section.

Consider this question: What do I want in a respite caregiver? If you were to describe the perfect caregiver for your child, what qualities would that person need? Would she need to be physically strong to lift your child? Would she need a car to get to your home? Would he need to be gentle? Is it more important that she be creative and fun-loving?

This question requires some thought and consideration. Right now, let's take a minute to think about these important qualities.



Important Qualities for Your Respite Caregiver continued

Give family members one minute to consider this question. At the end of the minute, ask:

You will want to take more time with this later. For right now, what did you come up with?

There are no overheads for this section.

Give everyone the opportunity to share at least one quality. After everyone has done this, conclude this section.

It is very helpful to think about these qualities before you begin your search for a caregiver for two reasons.

First, these qualities are quick checks for potential caregivers. They help you screen caregivers quickly and easily. If I need someone with a car, who can travel to my area, I can save time by asking potential caregivers whether they have use of a car in my first conversation with them. If they do not have a car, then I do not need to interview them.

Another way to find out if a caregiver has some of the qualities you are looking for is to use the Caregiver Profile in your Family Manual or ask a caregiver for their resume.



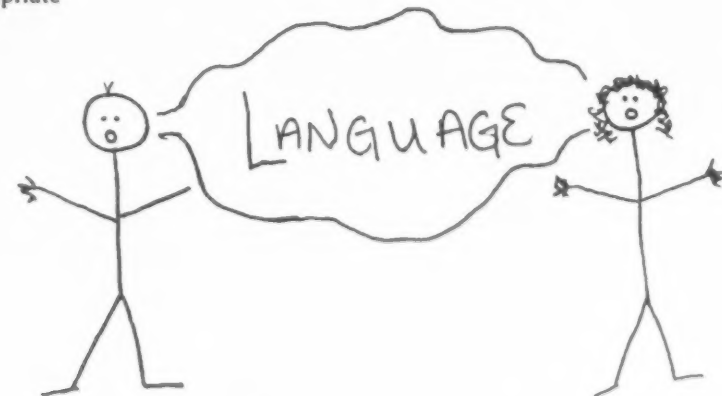
Important Qualities for Your Respite Caregiver continued

Make sure that families understand this concept of screening. You may need to give some more examples of screening questions, referring to the qualities families listed in their activity.

This process of quickly excluding unlikely matches is called "screening." It saves a lot of time for everyone. For example, if a family said that it was important that their caregiver had prior experience with children with autism, they should be sure to ask whether caregivers have that experience in their first conversation with them.

This list of qualities is also important in thinking about where to find appropriate caregivers for your child.

There are no overheads for this section.



5
mins

Circles of Family and Friends Activity

Introduce this activity by referring families to Circles of Family and Friends in Section 5 of the **Family Manual**.

Explain the information listed.

While other options are available to you. It is often best to match with a caregiver who already knows your family. These are people who already have a relationship with you and your child. You may already know someone who is a good match for you. Sometimes, these people are not obvious. But as you think about caregivers, think about people you know who have offered to help, or who have expressed an interest in your child. Maybe there is someone you have considered asking but did not because they did not have experience or special training to care for children with special needs. After you complete today's workshop, you will know how to train caregivers for your child.

Sometimes, it is difficult to think about who those people in your circle of family and friends might be. The circle chart in your **Family Manual** is designed to help you.

There are no overheads for this section.



Circles of Family and Friends Activity continued

Give families two minutes to brainstorm ideas from their circles of family and friends.

Encourage them to keep an open mind and think particularly about people who have asked how they can help.

At the end of the two minutes, ask them how they did. Encourage participants to share ideas to conclude the activity.

Think about yourself in the center of the center circle, where it says "Family." All around that circle are other circles, circles of family and friends. Fill in the lines by thinking about people in those circles who might be interested in providing respite.

As you do this, stretch your imagination. Who can you think of who has been friendly to you and your child? Who has your child already developed a relationship with?

Don't reject any idea until you are sure it will not work for you. I will give you a few minutes to fill in some of the lines in the circles.

Let's see how we did. Who would like to share what they learned?

There are no overheads for this section.



5
mins

Strategies for Finding Respite Caregivers

Recruiting from the Community

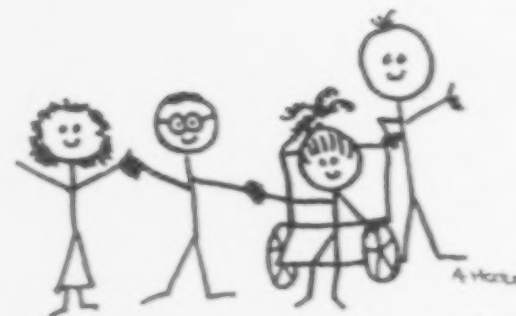
Refer families to Resources in Your Community in the **Family Manual**. Explain the information listed.

There are many agencies in this community that employ people who might be wonderful caregivers for your children. You can call these agencies and ask if they know of anyone on staff or in the community who might be interested in providing respite. They might take your name and have potential caregivers call you back.

Another way to access caregivers through these agencies is to ask if you can post flyers there. Make a colorful poster that describes your child's strengths and your family's desire to find a capable caregiver for your child. Remember, it is important to get permission to post flyers!

Think about your list of important qualities as you decide who to call and where to post information. If you need an energetic caregiver, college campuses are a good place to start. If, on the other hand, you need someone with a lot of experience in child care, you might start by asking at some local child care centers.

There are no overheads for this section.



Strategies for Finding Respite Caregivers continued

The Partners Directory, If Available

Note: Many communities choose to create a directory of Partners caregivers to distribute to families looking for caregivers. If this is true of your community, use this time to describe this directory to families.

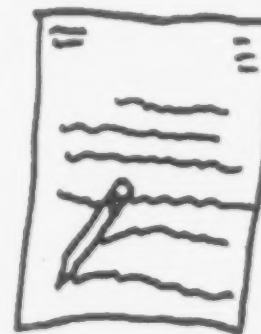
If the local Partners program fosters family/caregiver partnerships by planning matching events, be sure to mention it.

The Partners program has developed a directory of potential caregivers for families to access. But please note that Partners is not an employing agency. It does not license caregivers. In order to be included in the directory, caregivers need to ...

Families can get the following kinds of information from the directory ...

One of the best opportunities for finding a respite caregiver is by talking to some of the other participants in the session today. Families can exchange information and phone numbers if they find someone they think would be a suitable match.

There are no overheads for this section.



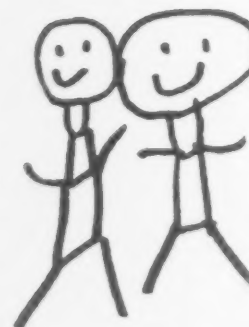
3
mins

Summary

Conclude the section by asking for group feedback.

Once you have a few ideas, you have the beginning of a potential list of caregivers. The next step is to talk to them about respite and to ask them if they would be interested in becoming a caregiver.

Are there any questions or comments on what we've discussed in this section? Would anyone like to share some additional ideas for finding caregivers that we haven't covered?



278

279

15
mins

Section 6 Families—Interviewing Caregivers

Objectives

- Prepare families to interview potential caregivers
- Identify what questions to ask caregivers in interviews
- Understand different options for conducting interviews
- Know other strategies for gathering information on caregivers

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 6, "Interviewing Caregivers," in the **Family Manual**.

Overheads are not necessary for Section 6 in the Family Break-Out Session. If you prefer, you may create overheads for your own use.

Corresponding Sections

Please refer participants to Section 6, "Interviewing Caregivers," in the **Family Manual**.



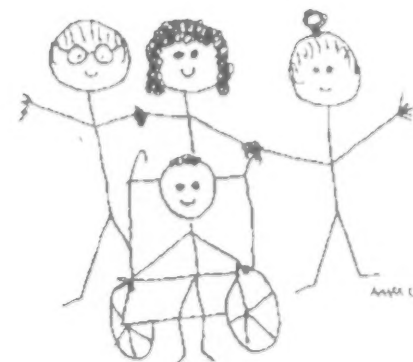
1
min

Introduction to Interviewing Respite Caregivers

Begin by explaining the interview process.

After finding a potential caregiver, and learning some preliminary information about her, the next step is the interview. You want to collect as much information as possible about a caregiver before you begin respite with her. In this section, we will talk about the different ways to interview a caregiver, provide you with some sample interview questions, and give you a few tips on getting the most information from a caregiver in an interview.

There are no overheads for this section.



282

283

10
mins

Conducting Interviews

Describe how to conduct interviews.

It is important to make interviews comfortable for both you and the caregiver. You can conduct an interview in a number of different ways. Some families choose to interview in their own homes. Some prefer to interview in the homes of the caregivers they are working with. Some like to work over the telephone. It is often helpful to see the caregiver in the environment where he will be working in respite.

We suggest that families interview more than one person and try and find as many caregivers as possible. In this way, you will have more people to call on when you need respite.

There are no overheads for this section.

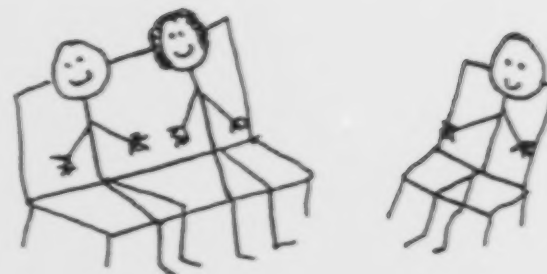


Conducting Interviews continued

Describe how to conduct interviews.

Also decide whether you want your children to be present for these interviews. Often, families find it useful to watch caregivers interact with their children. If your child's presence would be distracting, however, you may choose to hold a two-part interview. In the first part, you can sit down with a potential caregiver without your child present. At that time, the caregiver can answer any questions you have for her. If you feel the interview is going well, you can ask this caregiver to return so that she can meet your child. At that time, watch how she interacts with your child. Remember, she will not have the personalized training that she will need to work independently in respite. But this should give you an idea of how she works with your child on a natural level.

There are no overheads for this section.



Conducting Interviews continued

Remind families that caregivers may have some questions as well.

Define a successful interview. Refer families to "Interviewing Potential Caregivers" in their manuals.

Interviews are an important time for caregivers to get information on your family as well. Be prepared to answer questions that they might have about your children. Be very honest with caregivers about what will be expected of them. Emphasize your children's talents and strengths while, at the same time, being open about their special needs. This is the time when you and the caregiver decide whether you want to work together. By being honest, you will be sure that you both are committed to this respite relationship.

Successful interviews are those where families and caregivers learn what they need to know from each other in order to decide whether or not they are ready for a respite relationship.

There are no overheads for this section.



Conducting Interviews continued

Tips for Successful Interviewing

Refer participants to the Caregiver Profile in Section 9, "Forms for Sharing Information" in the **Family Manual**.

Partners has created a form for gathering relevant information about a potential caregiver, called the **Caregiver Profile**. If you find it useful, make copies for potential caregivers to complete before conducting an interview.

Here are some tips for making sure that your interviews are successful.

- **Be prepared.**

You may ask your applicants to give you a resume of their experiences with children or a **Caregiver Profile** before they come for an interview.

Make notes as you review this information.
What else do you need to know?

You may choose to use some or all of these questions in your interviews with caregivers. You may want to add some questions that are more specific to your child and family.

There are no overheads for this section.



Conducting Interviews continued

Continue discussing successful interview tips.

- Decide how to conduct the interview.

Again, talk with your caregiver about where and how to conduct the interview. Make sure that you schedule it at a time and place that are convenient for everyone. Decide before the interview who will be there. Some families like for both parents and the caregiver to have time alone to get to know each other. Sometimes the whole family is present for all or part of the interview. It is a courtesy to the caregiver to let them know how long the interview may take and who will be there.

- Break the ice.

Sometimes, it is difficult to know where to begin. It is useful to begin by asking the applicant to tell you about his experience with children.

There are no overheads for this section.



Conducting Interviews continued

Continue discussing successful interview tips.

- Ask open-ended questions.

An open-ended question is a question that is not answered with a yes or a no. They ask the applicant to provide more information. For example, "Do you like children?" is not a question that allows the applicant to give you a lot of information. "What do you like to do with children?" allows caregivers to expand on their skills.

- Take notes.

We suggest that families take notes or tape their conversations with caregivers. In this way, you can go back and ask follow-up questions to some of their statements. In addition, you can use those notes as you consider the applicants at a later time.

There are no overheads for this section.



Conducting Interviews continued

Continue discussing successful interview tips.

Refer families to Section 9, "Forms for Sharing Information." A form for checking caregiver references is included in this section.

- Reference checks.

It is a good idea to ask potential caregivers for references. These are people who know the applicant, and can comment on their character or their work with children.

When you call references, tell them who you are, and that you are considering hiring the applicant to provide care for your child. Ask if they have a few moments to speak with you. If they do, ask these questions, and any additional questions that you have about the applicant.

There are no overheads for this section.



Conducting Interviews continued

Continue discussing successful interview tips.

- Criminal record checks.

We would like to think that every applicant for child care positions are good people who love children. Unfortunately, some people want to work with children for the wrong reasons. There are some things that families can do to protect their children. The state police should be able to check the criminal records of potential caregivers. You will need to get forms from the police and ask applicants to sign them. Usually, there is a fee for this service, but a clean criminal record check may give you peace of mind.

Note: Some communities may be able to help families by sponsoring criminal record checks on their caregivers. If your program is able to do this, share that information with families now.

There are no overheads for this section.



Conducting Interviews continued

Refer families to "Additional Things to Consider" in the Partners Plus Family Manual.

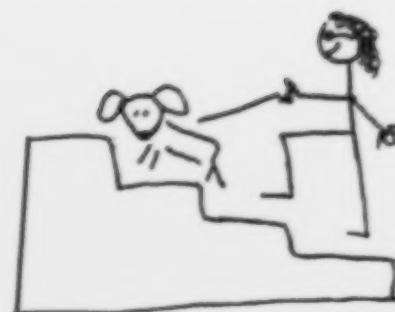
This section in your manual gives you information on some things to look for when you are interviewing caregivers. Included on these pages are some warning signs that may indicate a caregiver is not safe or appropriate for your child. Information about what to ask and look for in home and community-based caregivers is included. I encourage you to read this section carefully, and to use some of the questions listed here as you interview caregivers.

The most important tools that you have for protecting your children are your instincts. If you are uncomfortable with an applicant for any reason, that person is not the right caregiver for your family.

Explain how to conclude the interview.

After you have finished the interview, be sure to follow-up. Thank applicants for their time, and let them know how and when you will make your decisions. Do not leave an

There are no overheads for this section.



Conducting Interviews continued

It's important to be able to say "no" to caregivers who are not a good fit for your family.

applicant without a final decision on their application.

It can be very difficult to tell an applicant "no." However, it is important to be honest and direct.

This can be as simple as saying, "We interviewed several people, and we found someone else who we think best meets our needs."

There are no overheads for this section.



3
mins

Summary

Ask for group feedback.

Are there any questions or comments on what we've discussed in this section? I encourage you to take the time to read through all of the information included in this section in the manual.

Conclude the section by restating key points.

Feel free to write a note if you find saying "no" on paper is easier than saying it over the phone.

Interviewing is an important step in the Partners process. When you find a caregiver you feel comfortable with, offer her the job. After you agree to work together, get a clear idea of your caregiver's schedule and when and how she can and cannot provide care. You started to build your relationship in the interview.

Now, build on that relationship by making sure that she has the opportunity to set limits and schedule her time. The next step is training. When interviewing community program staff be sure to find out if they are willing to work with you in learning how to include your child in their program. The next step is to make a plan for how you will work together.

25
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Section 7 Families—Developing a Personalized Training Plan

Objectives

- Be prepared for personalized training with caregivers.
- Understand the four-step process for teaching daily routines to caregivers
- Know some principles for teaching adults
- Understand the importance of sharing emergency procedures and household rules with caregivers

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 7, "Developing Your Personalized Training Plan," in the **Family Manual**.

Overheads are not necessary for Section 7 in the Family Break-Out Session. If you prefer, you may create overheads for your own use.

Each community decides if they want to keep a resource library for caregivers and families. In this section, families get information on the Partners resource library. If your community has one, prepare to share information and material on accessing those resources.

Corresponding Sections

Please refer participants to Section 7, "Developing Your Personalized Training Plan," and Section 9, "Sharing Information with Caregivers," in the **Family Manual**.

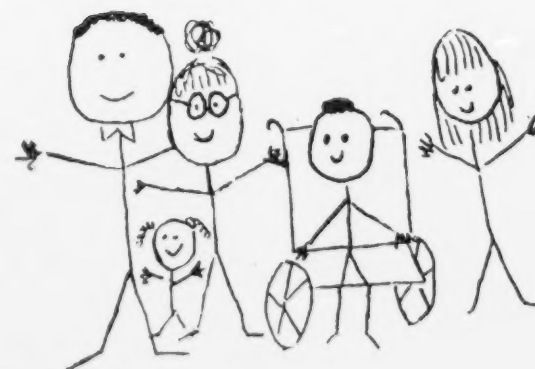
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Introduction to Developing a Personalized Training Plan

Introduce the personalized training plan concept.

The next step in the respite process is to teach your caregiver about your child and your family and your daily routines. In the next section, we will discuss a four-step process for developing a personalized training plan for your caregiver. We will also go over some tips on training adults.

There are no overheads for this section.



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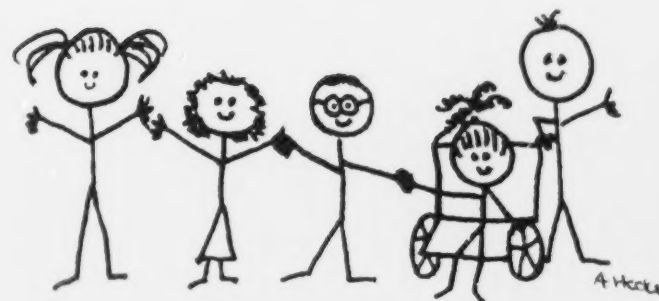
Four Step Process for Developing a personalized Training Plan

Introduce the four step process.

You can begin developing your plan by thinking about the time of day or time during the week you want care for your children.

Some families like to have respite in the evenings. Some families particularly want a Friday or Saturday night to go out. Some families need someone during the day during the week or on the weekends. When you are thinking about training a caregiver, be as specific as you can about when you want respite.

There are no overheads for this section.



Process for Developing a Personalized Training Plan continued

Ask for an example of a specific time from the group, and help participants think about all of the routines necessary for that time.

For any period of time, there are a number of routines that occur. Think about what happens in your family during the time you are planning respite. If respite takes place in a before- or after-school program, think about what happens during that time.

There are no overheads for this section.

Refer families to "Step by Step: A Guide to Developing Your Personalized Training Plan" in their manuals.

Will a caregiver need to learn a feeding routine? A play routine? Will a caregiver need to learn how to help your child interact with other children? Will a caregiver need to know how to adapt games in order for your child to fully participate? What about a special bedtime routine? A wake-up routine? A bathroom routine? A bath routine? A clean up routine? A medication routine? Think about everything a caregiver will need to know for this time with your child.

We suggest that you use this four-step process to train your caregiver. We will go through all of the steps.



Process for Developing a Personalized Training Plan continued

Step 1: Identify Training Goals

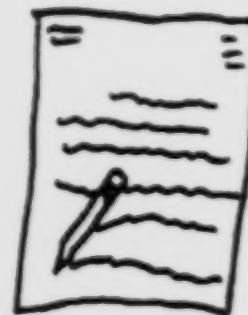
Refer families to "Step 1: Identifying Your Training Goals" in their manuals.

The first step is to identify training goals. What do you want your caregiver to learn to be able to provide care during this time? What are the routines that they need to learn?

One goal might be that you want your caregiver to know how to feed your child. Another goal might be that you want your caregiver to know how to help your child participate in an activity with other children. You can have as many goals as you need for personalized training.

There is a worksheet in Section 7 of the **Family Manual** for you to write down your goals for personalized training for a particular time of day.

There are no overheads for this section.



Process for Developing a Personalized Training Plan continued

Step 2: List Training Methods

Refer families to "Step 2: List Training Methods" in their manuals.

Define each of the methods listed.

The next step is to list training methods for each goal. What activities will you use to help the caregiver achieve the goal? There are many options.

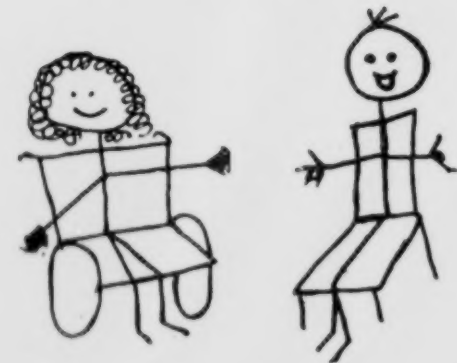
Modeling: A family shows a caregiver what to do.

Videotaping: A family videotapes a routine, enabling the caregiver to watch it again and again.

Shadowing: A caregiver helps the family work with their child. In this way, she gains hands-on experience but is not alone.

Talking, Telling, Describing: These are all ways that a family gives a caregiver information verbally.

There are no overheads for this section.



Process for Developing a Personalized Training Plan continued

Define each of the methods listed.

Writing: A family shares information with caregivers on paper.

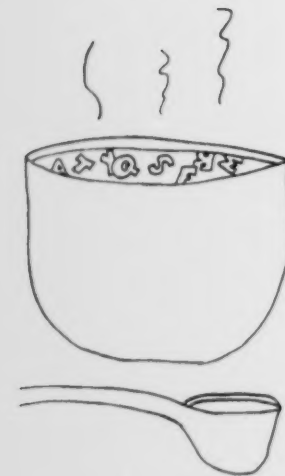
There are no overheads for this section.

Be sure to emphasize the following points.

Answering Caregiver Questions: A family responds to a caregiver's questions.

When teaching a caregiver your routines, try and remember how it was that you learned them. You may want to use those same methods to train your caregiver.

Remember that different people learn best in different ways. In the Caregiver Break-out Session, we ask caregivers to think about the ways that they learn best. Is it easier for them to hear information or to read it? Do they understand quicker if they watch someone perform a task or if it is described to them? Ask caregivers to share their learning styles with you, and use that information as you plan your training.



Process for Developing a Personalized Training Plan continued

Be sure to emphasize the following points.

Giving people information in a lot of different ways is usually more effective than giving them information in only one way. As you develop your plan, think about including more than one training method for each goal.

There is a worksheet in Section 7 of the **Family Manual** to help you think about what methods would be effective in teaching caregivers each goal.

Refer families to "Step 3: Use Resources to Help Train Your Caregiver" in their manuals.

The third step is to use resources to help train your caregiver. Resources are things that your caregiver can read, watch or look at that will give her extra information on working with your child and family. There are many different resources that you can use.

If your child is in a before- or after-school program that takes place in the same building where he attends classes, a teacher may be a helpful resource to program staff.

There are no overheads for this section.



Process for Developing a Personalized Training Plan continued

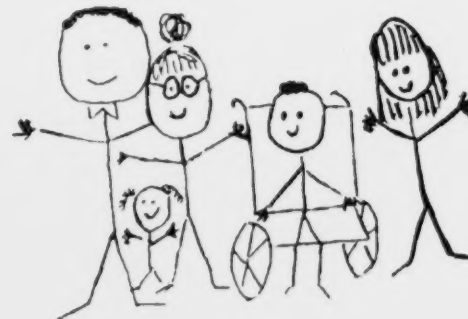
Refer families to "Sharing Information with Caregivers" in their manuals. Flip through the section with families as you make the following points.

You can create resources for your caregiver. The forms in this section are designed to help you think about the information your caregiver might want or need during respite. They address health, safety and medication issues for your child, information about your child's personality and skills, and other family information.

It is up to you whether you decide to use these forms. However, remember that caregivers will need all of this information.

The health and safety information is particularly important to caregivers. They need to know how to handle an emergency in your home. The list of phone numbers in your manuals should be as complete as possible. Cover all of the topics on the health and safety checklist. Do not place your child in the care of a caregiver who has not been prepared with this information!

There are no overheads for this section.



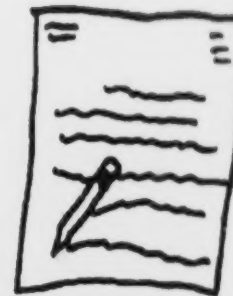
Process for Developing a Personalized Training Plan continued

Flip through "Sharing Information with Caregivers" as you make the following points.

There is a medical treatment release form in your manuals. This gives your caregiver permission to seek medical attention for your child in an emergency. Some medical care facilities will not treat children without the permission of a parent or legal guardian. This form is crucial to your child in an emergency. Keep it with other emergency information in a place where caregivers know to find it.

Feel free to create your own forms and documents as well. You may want to give your caregiver a diagram of how to position your child, for example. Or it might be important for them to have a map of the neighborhood. You might give them a videotape of your child's bedtime routine. Any of these resources can be valuable training tools.

There are no overheads for this section.



Process for Developing a Personalized Training Plan continued

Flip through "Sharing Information with Caregivers" as you make the following points.

There are many other resources that others have developed that can help you train your caregivers. There may even be some that others have developed specifically for your child. Think about sharing diagnostic reports, personalized plans, or suggested activities from your child's therapists with caregivers.

There are no overheads for this section.

You might also want to share general information on your child's condition. You may have books, magazines, or brochures in your home that could help a caregiver have a better understanding of your child.

Step 3: Use Resources To Help Train Your Caregiver

Refer families to "Step 3: Use Resources to Help Train Your Caregiver."

If you feel like some of this general information would be useful to caregivers, but you do not have it in your home, there is a list of places where you or your caregiver can find resources on this page.



Process for Developing a Personalized Training Plan continued

Note: In some communities, the Partners program has a library of resources that are available to families and caregivers. If your community has such a library, describe it now.

Describe the resources worksheet.

Step 4: Evaluation

Refer families to "Step 4: Evaluation" in their manuals.

Our program has a library of resources available for your use. To take advantage of this service . . .

In your manuals there is a worksheet to help you think about the resources you will use in your personalized training plan.

The final step of your training plan is evaluation. How will you and your caregiver know that the training goal has been accomplished and that the parents, caregivers, and children feel comfortable? There are many different ways to evaluate your caregiver's skills and knowledge. You might choose to ask your caregiver questions and make sure that she answers correctly. Another way is to ask a caregiver to show you a skill that you have taught him. You might just watch your child and caregiver for a time. Do they look comfortable with each other?

There are no overheads for this section.



Process for Developing a Personalized Training Plan continued

Describe Step 4.

Be sure to ask your caregiver to evaluate his knowledge and skill. He might want you to watch him do a task a few more times, or he might have some more questions to ask you. Make sure that he is comfortable with all of his responsibilities before you leave for respite.

There are no overheads for this section.

In your manuals there is a worksheet to help you plan your evaluation for your training.

Refer families to "Sample Personalized Training Plan" in their manuals.

On the following page there is a sample personalized training plan for lunchtime respite. Take a moment to read it now.

Give families time to read through the plan. Then ask for feedback.

Are there any questions about the four step process?

Later today, we will practice developing a personalized training plan using these four steps with the caregivers in the group.



Process for Developing a Personalized Training Plan continued

Ask if there is a person in the group who would be willing to volunteer to use one of their child's routines as an example for that activity.

If there are no volunteers, you can use an experience with a child you know as an example.

Is there is a person in the group who would be willing to volunteer to use one of their child's routines as an example for that activity? This is a great way for an individual family to begin to develop a plan. Some of the caregivers in the group might want to work with your child once they know a little about him or her.

There are no overheads for this section.



5
mins

Training Tips

Introduce this section.

Remind families that caregivers should have input in personalized training plans, as well.

Refer families to "Training Tips" in their manuals.

Training adults is a slightly different experience than teaching children. This section in your manual also includes some tips for training adults.

Caregivers may want to be involved in planning personalized training. They may have specific ideas about what activities or resources will be helpful to them. Invite them to share this information and their other ideas.

Turn to Section 7 in your manuals for some training tips. The tips on this page will help make your training effective.

There are no overheads for this section.



Training Tips continued

Review training tips with families.

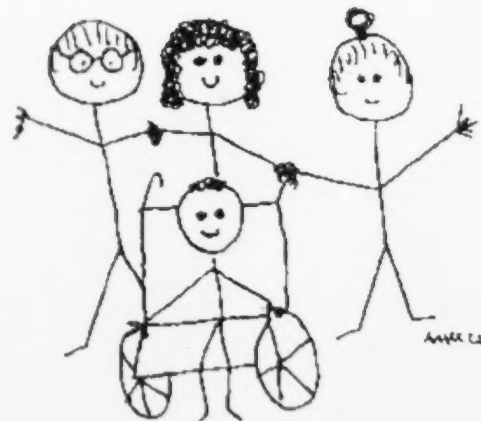
- Be clear with your instructions.

Be certain that a caregiver understands the words that you use to describe your child, her condition, and household equipment. If necessary, show caregivers things that might cause them confusion.

- Be very specific.

When you are training, think about the details of your care of your child. It may be that your child wears a bib for meals. Which bib is her favorite? Which bib does she never wear? Give this information to caregivers. Also, be careful that you do not assume that a caregiver knows where you keep things. Show her exactly where equipment and supplies are.

There are no overheads for this section.



Training Tips continued

Review training tips with families.

- Use your knowledge and resources to train.

Again, think about how you learned about your child. Adapt these methods to your style of teaching.

- Give your caregiver written information.

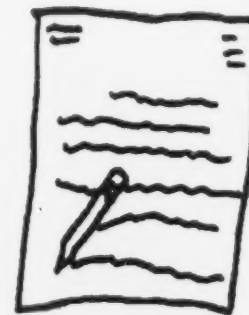
Written information is helpful because it can be taken home and studied and referred to at a later time.

- Talk to your caregivers about the information that you give them.

A caregiver may have additional questions and comments about what he has read or heard from you.

- Make sure that he has the opportunity to learn more from you. Check to make sure that he is feeling comfortable with new skills and tasks.

There are no overheads for this section.



Training Tips continued

Review training tips with families.

- Use diagrams or pictures.

Some people learn better from pictures. Include these in your training resources if they are appropriate.

- Be sure to get feedback from your caregiver.

Find out what is helpful and not helpful to caregivers in training.

- Write down important facts or information.

Again, this information should be easy for caregivers to study and come back to at a later time.

- Share information about your culture, or life ways (how your customs reflect your culture and your values), that is important to your family.

This information will give a caregiver guidelines for working with your child and planning activities.

There are no overheads for this section.



Summary

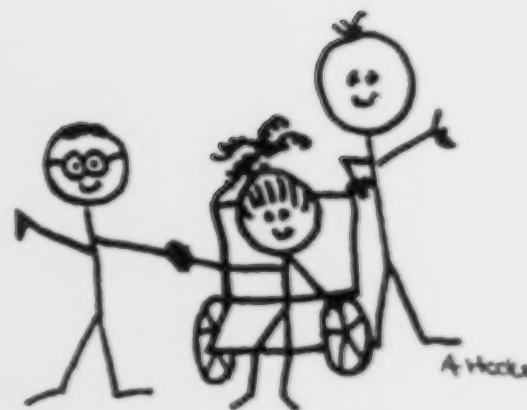
Ask the group for feedback.

Are there any questions or comments about this section?

Prepare the group for the next step.

The next step is to use your personalized training plan to teach your caregiver about your child and your family. With its use, your caregiver should be well prepared to care for your child.

Remember that the kind of communication that occurs during training should continue throughout your relationship. Share new information with your caregiver. Caregivers may even have information to share with you! Personalized training should never end. Part of sharing a partnership is continually learning more about one another and your child.



15
mins

Section 5 Caregivers—Disabilities Awareness

Objectives

- Identify terms, services, and issues related to children with special needs
- Understand common terms, services, and major issues related to children with special needs.

Preparations

Read the Introduction to this manual, the "Overview of the Section" and the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 5, "Disabilities Awareness," of the **Caregiver Manual**.

The information on services and legislation in this section is accurate as of the day of printing. Please be aware that legislation and the provision of services for children with special needs are ever-changing. Please keep your materials up-to-date for families and caregivers.

Prepare overhead transparencies of:

- Overhead Partners Plus Caregiver IDEA (Individuals with Disabilities Education Act) 5-1
- Overhead Partners Plus Caregiver Plan 5-2
- Overhead Partners Plus Caregiver IFSP / IEP 5-3
- Overhead Partners Plus Caregiver Early Intervention and Public School Services 5-4
- Overhead Partners Plus Caregiver Common Disability Issues 5-5

Corresponding Sections

Please refer participants to Section 5, "Disabilities Awareness," in the **Caregiver Manual**.

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Introduction to Disabilities Awareness

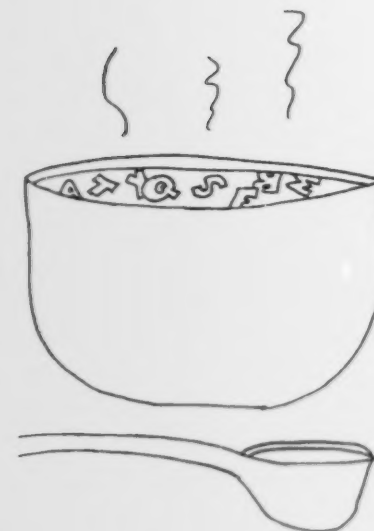
Introduce the section. Refer caregivers to Section 5, "Disabilities Awareness" in the **Caregiver Manual**.

As you work with children and families, it can be very helpful to have an understanding of some of the terms, issues, and services for people with special needs.

Every day with a child with special needs is a day of learning: about the child, about how to help her in her development, and about how to get the services available to her. Often, when you hear a family of a child with a disability speak about these experiences, it is like you are hearing a whole new language. Families had to learn this language, too, and it is a tool that they use to communicate about their children.

You can think about this language as a kind of alphabet soup. Before you learn what the terms stand for, they look and sound like a jumble of letters. As we go through some of these terms, think about what it feels like for families new to the experience of raising children with special needs to be faced with all of this confusing language! They have to learn fast!

There are no overheads for this section.



6
mins

Services for Children with Special Needs

Introduce this section.

Refer to overhead Partners Plus Caregiver IDEA 5-1. Participants may wish to follow along in Section 5 of the **Caregiver Manual**.

Many of these terms are related to intervention and education for children with special needs.

The first term, "IDEA" is an acronym that stands for the Individuals with Disabilities Education Act. IDEA is a federal law that guarantees that children with special needs receive services. It is broken down into several parts, which guarantee special services for children at different ages.

One part, Part C, says that infants and toddlers from birth to age two with disabilities or developmental delays may receive early intervention services. I will describe these in more detail in a moment.

Overhead Partners Plus Caregiver IDEA 5-1

IDEA (Individuals with Disabilities Education Act)

Birth through 2: Early Intervention
Services (EI)

Ages 3-21: Free and Appropriate Public
Education (FAPE)

Ages 3-5: Early Childhood Special
Education (ECSE)

Ages 5-21: Special Education

Services for Children with Special Needs continued

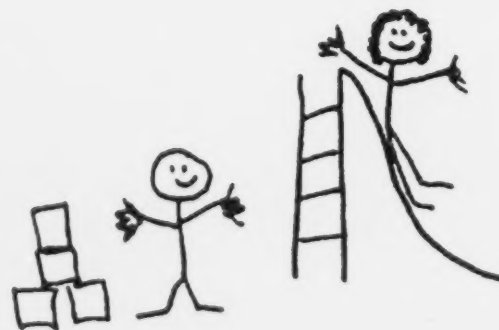
Continue with the discussion on IDEA.

Another part, Part B, guarantees eligible children from three to 21 years free and appropriate public education (FAPE). Children from three to five years old receive early childhood special education (ECSE) services. The services provided to older children are simply called special education services.

It is important to remember that each state has different rules about eligibility for services.

IDEA also says that children who are eligible for services must have a written plan that is reviewed at least once a year.

There are no overheads for this section.



Services for Children with Special Needs continued

Refer to overhead Partners Plus Caregiver Plan 5-2. This information is in Section 5 of the **Caregiver Manual**.

The plan is written by a team that includes family members and other people working with a child. Teams can include teachers and special educators, physical, occupational and/or speech therapists, doctors or nurses, and counselors or social workers. The plan that the team writes includes information about the child's development, specific goals or outcomes for the child, and the activities that the team members will use to help the child reach the goals. Family members are crucial members of these teams, and must agree to the plan written for their child.

Overhead Partners Plus Caregiver Plan 5-2

Plan

Plan includes:

- Information about the child's development
- Goals for each child
- Activities to help the child achieve the goals

Services for Children with Special Needs continued

Refer to overhead Partners Plus Caregiver IFSP/IEP 5-3.

In early intervention services for young children, the plan is called an IFSP: an Individualized Family Services Plan. In services for children beyond age three, the plan is called the IEP, or Individualized Education Program.

Reviewing an IFSP or IEP can be very helpful in planning activities for respite. Keep in mind, however, that the information included in these plans is personal and confidential, and families might prefer that you not read them.

While early intervention and special education are all parts of IDEA, and they provide many of the same services, the programs often look very different.

Appropriate services for each child are determined by the members of their planning teams. Services for all IDEA programs can include home visits, classroom programs or play groups, and therapies.

Overhead Partners Plus Caregiver IFSP/IEP 5-3

IFSP

Individualized Family Service Plan:

- For early intervention
- Serving the child within the context of the family

IEP

Individualized Education Plan:

- For preschool service and beyond
- Serving the child within the context of the school system

Services for Children with Special Needs continued

Refer to overhead Partners Plus Caregiver Early Intervention and Public School Services 5-4.

Early intervention is a family-centered program, like Partners. As a result, IFSPs, the plans written for children in early intervention, can include many different kinds of services. Family support groups are one of the services offered by many early intervention programs.

In ECSE and special education programs, however, the focus of the plan and services changes. These programs focus on education, and the services provided are those that will help children benefit from school. A child may get physical therapy to help her move from place to place in a classroom or hold a pencil; but services to support families in a larger sense are more limited.

Remember, too, that the planning team decides services under local, federal and state guidelines. As children age, their services often look very different, even if their primary concerns remain the same. In addition, when families move from place to place, services for their children can be determined under very different guidelines, as each state and locality is different.

Overhead Partners Plus Caregiver 5-4

Early Intervention and Public School Services Can Include:

- Home visits
- Classroom programs
- Play groups
- Therapies
- Groups for Families

5
mins

Common Disability Issues

Introduce the concept of transition.

Refer to overhead Partners Plus Caregiver Common Disability Issues 5-5. The first issue listed, Transition, is described in Section 5 of the **Caregiver Manual**.

When we think about issues that affect children with disabilities and their families, then, we want to include moving from program to program, or "transition," as a common issue for families.

While families are often very happy to see their children grow and graduate from early intervention services, they are asked to learn about very different programs with very different rules and different staff members all at the same time. While they may be pleased to move, they might be nervous about what services for their children will be like in unfamiliar communities.

Transition can be very difficult for families, and caregivers may need to be supportive of families as they learn about their new situations.

Overhead Partners Plus Caregiver 5-5

Common Disability Issues

- Transition
- Accessibility
- Language

Common Disability Issues continued

Introduce the concept of accessibility. Accessibility is discussed in Section 5 of the Caregiver Manual.

People with special needs also face discrimination. In 1990, The American with Disabilities Act (or the ADA) was signed into law. For the first time, that legislation outlawed discrimination of people with disabilities. One of the issues that it addresses is accessibility. Under this law, places that the public uses must be accessible. That is, people with disabilities must be able to use them. People who use wheelchairs, for example, cannot use buildings where there are steps to the front door and no wheelchair ramps. Signs that do not include braille writing are unreadable to people with severe visual impairments. ADA was enacted to encourage people to make their facilities accessible.

Despite the passage of the ADA, however, many businesses and agencies have yet to make their facilities accessible because of federal waivers, exemptions, the burden of cost, time lines, etc. Accessibility continues to be an issue for many children and families.

Overhead Partners Plus Caregiver 5-5

Common Disability Issues

- Transition
- Accessibility
- Language

Common Disability Issues continued

The final issue, Language, is addressed in Section 5 of the **Caregiver Manual**.

Using "people first" language when you are working with children with disabilities is helpful and respectful.

Make sure that participants understand this point. Use the examples listed in Section 5 of the **Caregiver Manual** for practice. Go over these with participants to make sure everyone understands.

A third issue is language. As you work with families, listen to the words that they use to describe their children and conditions. Sometimes, people choose those words for very important reasons.

At one time, people with disabilities were called "handicapped" or "disabled." In recent years, people with disabilities have told us that they feel that these terms are very limiting. They would like people to use language that describes them as people first before describing their condition.

When using people-first language, instead of saying, "the disabled man," we say "the man with a disability." Let's go over a few examples from your manuals. Turn to Section 5.

Overhead Partners Plus Caregiver 5-5

Common Disability Issues

- Transition
- Accessibility
- Language

Common Disability Issues continued

Follow the family's lead regarding the use of people-first language.

Some families will not use people-first language, and you can feel free to adopt their way of describing their children. It is crucial to be sensitive to the people you work with. Listen carefully to what they say, and if they ask you to use different language, be sure to do that.

Overhead Partners Plus Caregiver 5-5

Common Disability Issues

- Transition
- Accessibility
- Language

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Summary

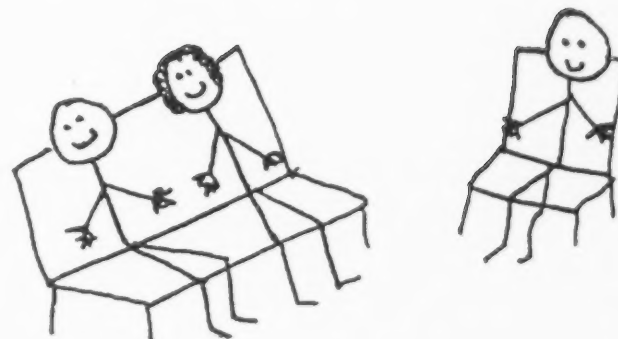
Ask the group for feedback.

Does anyone have any questions or comments about the information presented in this section? I encourage you to read through the information in the manual for more information on disabilities awareness.

Conclude the section by reinforcing key concepts.

Families and children with disabilities have far more options today than they did 20 years ago. As caregivers, you are in a strong position to advocate for the children you work with and their families. Let families know that they have rights under the law.

Encourage businesses in your community to make their facilities accessible to people with disabilities. IDEA and the ADA were made into law because people with disabilities and their families and friends took a stand. Your voice is important!



**Section 5 Caregivers—Disabilities Awareness
Suggested Overheads**

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IDEA

(Individuals with Disabilities Education Act)

Birth - 2:

- Early Intervention Services (EI)

Ages 3-21:

- Free and Appropriate Public Education (FAPE)

Ages 3-5:

- Early Childhood Special Education (ECSE)

Ages 5-21:

- Special Education (SpEd)

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Partners Plus Workshop
Caregiver Manual Section 5

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 5-1 C

Plan

Includes:

- information about the child's development
- goals or outcomes for the child
- activities to help the child achieve the goals

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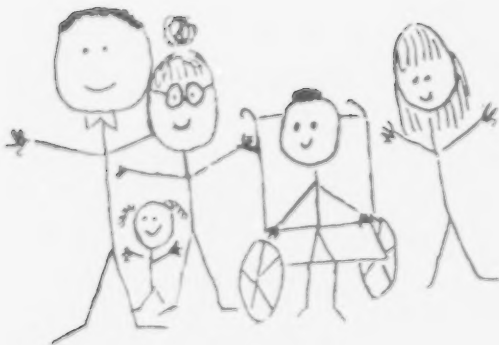


IFSP

Individualized Family Service Plan

(for early
intervention)

**Serving the child
within the context
of the family.**

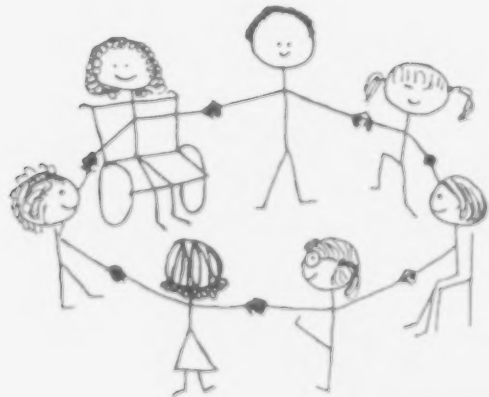


IEP

Individualized Education Plan

(for preschool
service and beyond)

**Serving the
child within the
context of the
school system.**



DRAFT 10.99



**Partners Plus Workshop
Caregiver Manual Section 5**

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 5-3 C

Early Intervention and Public School Services

can include:

- **home visits**
- **classroom programs**
- **play groups**
- **therapies**
- **groups of families**

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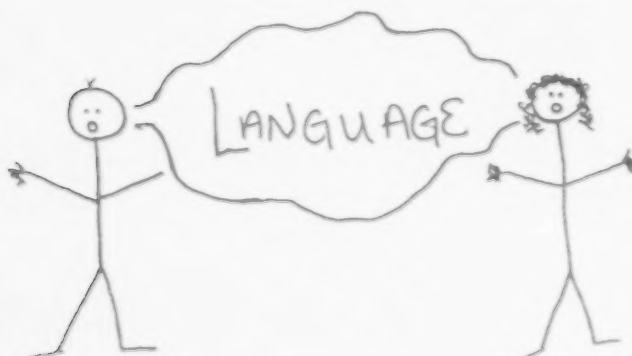
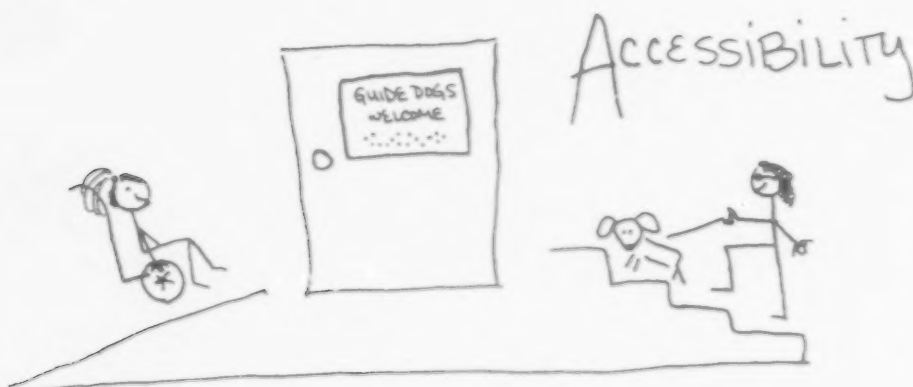
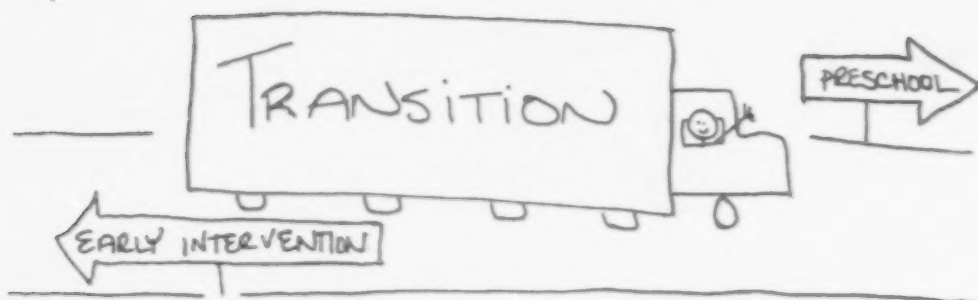


**Partners Plus Workshop
Caregiver Manual Section 5**

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 5-4 C

Common Disability Issues



DRAFT 10.99



Partners Plus Workshop
Caregiver Manual Section 5

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 5-5 C

15
mins

Section 6 Caregivers—Understanding Child Development

Objectives

- Learn information on child development and planning appropriate activities for children
- Understand the basics of child development
- Use knowledge about child development to work effectively with children
- Be aware of the importance of play and enriching environments for child development
- Be aware of potential hazards in an environment and appropriate safety precautions

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 6, "Understanding Child Development," of the **Caregiver Manual**.

Prepare overhead transparencies of:

- Overhead Partners Plus Caregiver Areas of Development 6-1
- Overhead Partners Plus Caregiver Areas of Development 6-2
- Overhead Partners Plus Caregiver Guidelines for Caregivers' Involvement in Play 6-3

Corresponding Sections

Please refer participants to Section 6, "Understanding Child Development," in the **Caregiver Manual**.

2
mins

Introduction to Child Development

Introduce the concepts of the section.

Providing respite care for children with special needs is not so different from caring for children who are typically developing. Respite caregivers who work with children who have special needs do require some special information and skills to do their job effectively. However, the most important knowledge in caring for children is understanding child development. It is important to know how children grow and learn new skills in order to be able to plan enjoyable and challenging activities for them.

At each age, we expect children to reach certain developmental milestones. For example, we expect to see children take their first steps at around a year old.

There are no overheads for this section.



Introduction to Child Development continued

Continue introducing the concept of child development.

Children with special needs may reach certain milestones later than other children. For example, a child with cerebral palsy might walk later, and a child with a cleft palate might say her first words later. Sometimes, children with special needs do not reach milestones at all.

It is important to remember that development follows a logical order for all children. A person of any age must be able to hold her body up before she can stand.

There are no overheads for this section.



2
mins

Planning Appropriate Experiences

We need to understand the order in which we can expect to see different skills develop in children so that we know what children can be expected to learn.

Offer an example to illustrate this point.

For example, a very young child first plays alone. Next we expect a child to play with toys close to other children, before being ready to join in play with one or more children.

When we know the range and sequence of typical development, we are able to know what skills we can help a child learn with success and what activities to plan.

There are no overheads for this section.



Planning Appropriate Experiences continued

Explain how to plan activities that give children with disabilities a chance to use their developmental strengths.

Offer an example to illustrate this point.

Many children with disabilities have some areas of development in which their skills are similar to those of their peers. Emphasizing those strengths is important to each child's confidence and overall development.

For example, a 4-year-old child with mental retardation may not be able to play with others or take part in social activities typical for children her age. However, the way she uses her body may be typical. She can climb on play equipment, ride a trike, and run and jump like other children her age. Giving her opportunities to practice using her muscles will help her to continue developing her abilities, help her to feel good about herself, and give her ways to play with other children. You can help her expand her social skills by building on her strengths, playing near or with other children on playground equipment.

There are no overheads for this section.



Planning Appropriate Experiences continued

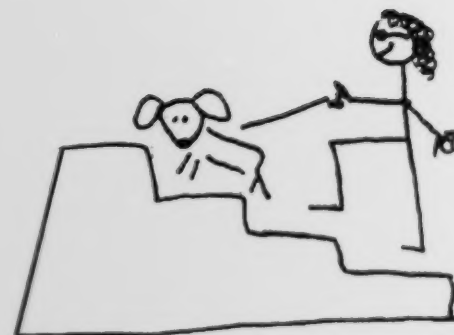
Describe how a child with a visual impairment can take the lead in a game like pinata.

In games where groups of school-aged children participate, caregivers can find opportunities for children with disabilities to take the lead and demonstrate their abilities among peers. A child with visual impairment whose motor skills are like that of their peers could take the lead in a game of pinata. In this game, a brightly colored ornament is suspended above children's heads, and blindfolded players take turns hitting it with a stick to break it open. Taking the lead in this game helps the child gain confidence and build self-esteem.

Make sure that participants understand these principles before going on to the Basic Principles of Child Development.

Are there any questions on this material?

There are no overheads for this section.



This information was adapted from Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *Specialcare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.

10
mins

Basic Principles of Child Development

Introduce the basic principles of child development.

Child development is an orderly sequence of physical, intellectual, and emotional change that occurs throughout childhood. Although a child develops as a whole person, different words and categories are used to describe different areas of development.

For a child with a disability, understanding the different areas of child development will help us understand the child's development. However, a disability in one or more areas of development frequently affects other areas of development as well.

There are no overheads for this section.



Discuss the five areas of development. Refer to overhead Partners Plus Caregiver Areas of Development 6-1. Refer participants to Section 6 in the **Caregiver Manual**.

To make this section of the Partners workshop more participatory you can ask participants to share what the area of development means to them, filling in as needed from the didactic script.

As children grow older, they change in all kinds of ways. There are five different areas of development. Caregivers can plan activities that will support children in all of these areas of development.

The first area of development is physical development. Physical development refers to the way the child's body grows and functions.

Gross motor development is a type of physical development. When we talk about gross motor development, we are referring to the ways that children use their big muscles to support and move their bodies.

Overhead Partners Plus Caregiver 6-1

Areas of Development

Physical Development:

- Gross Motor
- Fine Motor
- Vision
- Hearing

Communication Development:

- Receptive Language
- Expressive Language

Basic Principles of Child Development continued

Discuss the five areas of development.

Fine motor development refers to how children use their small muscles (their fingers and their tongues) for activities such as grasping small objects, coloring, turning knobs, and chewing and swallowing.

Vision refers to how children see.

Hearing refers to how children hear.

Communication development refers to the way that children understand messages and let us know what they want, need, or understand. There are two parts of communication development: receptive language and expressive language.

Receptive language describes the way that children understand messages from others.

Expressive language describes how children get their messages across - through sounds, gestures, words, signing, or the use of communication devices.

Overhead Partners Plus Caregiver 6-1

Areas of Development

Physical Development:

- Gross Motor
- Fine Motor
- Vision
- Hearing

Communication Development:

- Receptive Language
- Expressive Language

Basic Principles of Child Development continued

Discuss the five areas of development.

Children learn receptive language before they learn expressive language. A young child will understand the sentence "Go get the ball" long before he will be able to say that sentence or even the word "ball."

Refer to overhead Partners Plus Caregiver Areas of Development 6-2.

Cognitive development describes the way that children think and solve problems.

As you work with children, think about how they use their brains to play with the toys that they enjoy.

Many activities that caregivers do with children help support cognitive development. For example, pop-up boxes, toys where children push buttons or twist knobs to make animals pop out, teach children that their actions cause other things to happen. Understanding cause and effect is one important cognitive milestone.

Overhead Partners Plus Caregiver 6-2

Areas of Development
Cognitive Development
Adaptive Development
Social or Emotional Development

Basic Principles of Child Development continued

Discuss the five areas of development.

Adaptive development refers to the way that children take care of their personal needs. As you work with children, ask yourself: How do these children get dressed, feed themselves, brush their teeth? Learn from families what their children can do for themselves in this area. Encourage their independence as much as possible!

Social or emotional development refers to the way that children think and feel about themselves and the people around them. It also refers to the way children form relationships with the people in their lives.

Caregivers can promote social and emotional development by offering children encouragement and care.

Overhead Partners Plus Caregiver 6-2

Areas of Development
Cognitive Development
Adaptive Development
Social or Emotional Development

Basic Principles of Child Development continued

Emphasize the following points.

Children with special needs sometimes have "delays" in development. They may not reach developmental milestones at the same time other children typically do. Caregivers can work with families to help support children as they try to reach developmental milestones.

Delays in one area can affect development in another area. For example, a child with significant physical delays may not be able to play on the slide without extra support. What happens when everyone else is playing on the slide and this child is not? He is missing out on the opportunity to work on his social skills in play with these other children. A caregiver can physically support the child so that he, too, can enjoy the slide and the social play.

Children with special needs also have strengths. Attend to children's strengths and build on them. A child who is showing

Overhead Partners Plus Caregiver 6-2

Areas of Development

Cognitive Development

Adaptive Development

Social or Emotional Development

Basic Principles of Child Development continued

Discuss the five areas of development.

language delays might have strong muscles. Suggest to her family that you take her to the playground. As she is playing, label objects for her to help her language development. Encourage her to play with other children, so she can hear their language and develop social skills. Praise her efforts! All of these activities build on her strong muscles and support her development in other areas as well.

Discuss the importance of play. Refer to overhead Partners Plus Caregiver Guidelines for Caregivers' involvement in Play 6-3. Refer participants to Section 6 in the Caregiver Manual.

One of the best ways to support the development of children is to play with them. Play is a child's work, and it is what we use to help children achieve developmental milestones. There are a few simple guidelines for playing with children.

First, it is important to observe the child as he plays. Note what skills he is using, and what activities he enjoys. This information will be helpful later, as you plan activities

Overhead Partners Plus Caregiver 6-3

Guidelines for Caregivers' Involvement in Play

- Observe
- Follow
- Be Creative
- Be Safe
- Have Fun!

Basic Principles of Child Development continued

Discuss the importance of play.

with him. In play, you can help him build on his skills using activities you know he enjoys.

Join the play when the child invites you. As you play, make sure that you are playing at the child's level. Let the child be in charge! Follow her lead!

Be creative in your play! There are lots of different ways to play and learn. Think about a shoe box.

As caregivers answer, ask them to think about what areas of development are being used in the activities they describe.

How many different ways can you play with a shoe box?

What areas of development are being used when we play with the box this way?

Overhead Partners Plus Caregiver 6-3

Guidelines for Caregivers' Involvement in Play

- Observe
- Follow
- Be Creative
- Be Safe
- Have Fun!

Basic Principles of Child Development continued

Discuss how play uses various areas of development.

Show caregivers how they can use this activity to work on other areas as well.

Usually, play involves more than one area of development. Hiding an object under a shoe box, for example, encourages physical development (as the child lifts the box and grasps the object) and cognitive skills (as the child tries to find the object).

You can use play to work on other areas, as well. By labeling the object and the box, caregivers encourage communication development. By clapping when the child finds the object, the caregiver encourages emotional development.

So, with a little creativity, you can work on all of the areas of development with just a shoe box!

There are no overheads for this section.



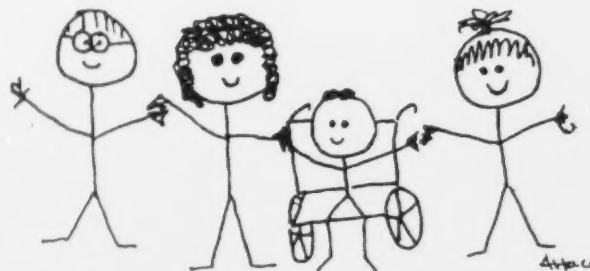
Basic Principles of Child Development continued

Discuss guidelines for play.

The next guideline is to be safe. Before you begin respite, discuss safety issues with families. What might put their children in danger? What should you watch for? Examine the space you will be using to provide care. Are knives and dangerous tools safely stored? Are electrical outlets covered? Are glass trinkets on low tables where children can break them? Are there sharp corners to watch for? Where will you go in case of fire? Some caregivers find it helpful to get down on their hands and knees to examine the space from the child's perspective. There is also a safety checklist included in the **Caregiver Manual**. When you are planning care with a family, read over this checklist and discuss it with the family.

The last guideline is to have fun!

There are no overheads for this section.



3
mins

Summary

Ask the group for feedback.

Are any questions or comments on this section? I encourage you to read through Section 6 in the **Caregiver Manual** for more information on child development.

Conclude the section with a summary statement.

Respite is a wonderful experience when you are meeting a child at his own level, challenging him, playing with him, and watching him build skills. Awareness of child development is the key to this kind of experience!



Section 6—Understanding Child Development Suggested Overheads

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Areas of Development

Physical Development

- Gross Motor
- Fine Motor
- Vision
- Hearing

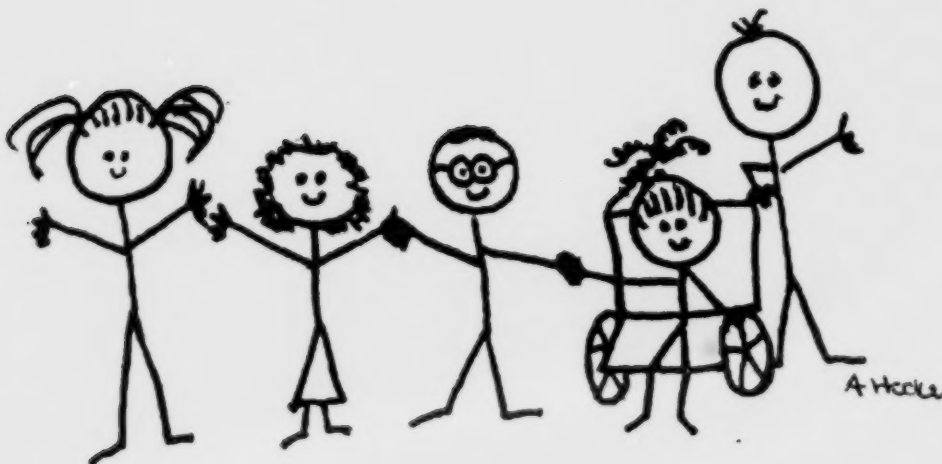
Communication Development

- Receptive Language
- Expressive Language



Areas of Development

- Cognitive Development
- Adaptive Development
- Social or Emotional Development



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Partners Plus Workshop

Caregiver Manual Section 6

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

412

PP 6-2 C

Guidelines for Caregivers' Involvement in Play

Observe

Follow

Be Creative

Be Safe

Have FUN!



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**Partners Plus Workshop
Caregiver Manual Section 6**

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 6-3 C

15
mins

Section 7 Caregivers—Children with Special Needs

Objectives

- Understand basic information about common special needs
- Be aware of the basic developmental and medical effects of common special needs on children
- Understand what caregivers may be asked to do when they care for children with common special needs

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 7, "Children with Special Needs," in the **Caregiver Manual**.

Prepare overhead transparencies of:

- Overhead Partners Plus Caregiver Common Disabilities 7-1
- Overhead Partners Plus Caregiver Common Disabilities 7-2
- Overhead Partners Plus Caregiver Common Special Health Care Needs 7-3
- Overhead Partners Plus Caregiver Common Special Health Care Needs 7-4

Corresponding Sections

Please refer participants to Section 7, "Children with Special Needs," in the **Caregiver Manual**.

2
mins

Introduction to Children with Special Needs

Introduce the concepts of the section.

Another useful tool for caregivers in respite is a basic understanding of common special needs.

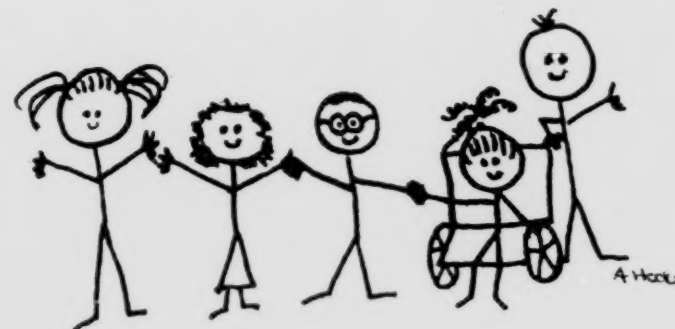
There are no overheads for this section.

Refer caregivers to Section 7 of their manuals: Children with Special Needs.

In this section in your manual, there is some basic information on working with children with specific special needs. As we do this, remember these three things:

1. The best source of information about a particular child and his diagnosis is that child's family.
2. Through the Partners model, you have choices about working with particular children and families.
3. There is a wide range of special needs.

Let's talk about each of these items separately.



Introduction to Children with Special Needs continued

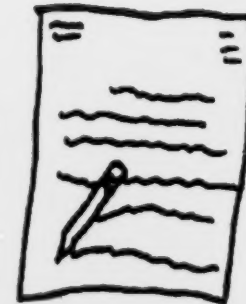
Describe the three main points to remember when working with children with special needs.

First, the best source of information about a particular child and his diagnosis is that child's family. The same condition can affect individual children differently. While I will give you some general information today, pieces of it may not apply to certain children. Take your cues from families about how to work with their children.

Second, through the Partners model, you have choices about working with particular children and families. If you feel uncomfortable about working with a child with a particular diagnosis for any reason, discuss it with her family. All we ask is that you keep an open mind and see what you learn!

Third, there is a wide range of special needs. While we will talk briefly about common special needs today, we will not be able to discuss everything. Please take the time to read this information and the information in the Resources section of your manual thoroughly. Your manual lists places where you can gather more information if you want to do so.

There are no overheads for this section.



Common Disabilities

Refer to the overhead Partners Plus Caregiver Common Disabilities 7-1. The information in this section corresponds with Section 7 of the **Caregiver Manual**.

Work your way through the disabilities, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

This is a list of the disabilities that we commonly hear about. In the next few minutes, we will briefly describe each diagnosis and talk a little bit about special things caregivers might need to do for children with those conditions.

Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD):

Children with ADD or ADHD have very short attention spans. They often have difficulty focusing on tasks, and may act on impulse. Children with ADHD may be physically active as well.

Caregivers may need to work with families to make sure that children with ADD or ADHD have consistent, structured routines. In addition, in some cases, caregivers may need to learn medication routines for these children.

Overhead Partners Plus Caregiver 7-1

Common Disabilities

- Attention Deficit Disorders
- Autism
- Blindness / Visual Impairment
- Deafness / Hearing Impairment
- Emotional Disturbance

Common Disabilities continued

Work your way through the disabilities, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

Autism:

Autism is a condition that affects a child's brain. Children with autism often have trouble with social and communication skills.

Caregivers may need to learn to communicate with these children and closely watch their interaction with other people. Children with autism also tend to respond well when caregivers structure their routines.

Blindness/Visual Impairment:

These diagnoses tell you that the children you are working with have trouble seeing. Visual impairments are less severe than blindness, and more common. Children with visual impairments have some level of vision.

As a caregiver, find out what a child can and cannot see. Adapt activities to make sense for them. If you are working with

Overhead Partners Plus Caregiver 7-1

Common Disabilities

- Attention Deficit Disorders
- Autism
- Blindness / Visual Impairment
- Deafness / Hearing Impairment
- Emotional Disturbance

Common Disabilities continued

Work your way through the disabilities, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

children with visual impairments in a space that is unfamiliar to them, you want to stay close to them as they learn about this new space.

Try to keep furniture and objects in the same places each time.

Deafness/Hearing Impairment:

Deafness is the inability to hear. Again, hearing impairments are less severe than deafness.

Caregivers for children with these diagnoses should learn how to communicate with them. How do they communicate with others? It may be that you will have the opportunity to learn a whole new language!

Emotional Disturbance:

Children with emotional disturbance usually have trouble with social skills or

Overhead Partners Plus Caregiver 7-1

Common Disabilities

- Attention Deficit Disorders
- Autism
- Blindness / Visual Impairment
- Deafness / Hearing Impairment
- Emotional Disturbance

Common Disabilities continued

Work your way through the disabilities, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

Refer to overhead Partners Plus Caregiver Common Disabilities 7-2.

with making friends. There are many different types of emotional disturbance.

As a caregiver, you will need to learn specifically how a child with emotional disturbance is affected and how you can best support them.

Learning Disability:

Learning disabilities cause children to have trouble with reading, writing, math, listening, speaking or using logic. These children generally do poorly in school, but they may be very smart. Their brains simply have trouble understanding or sending information. There are many different kinds of learning disabilities.

Caregivers should learn more specifically what kinds of learning disabilities the children in their care have. Find out from families how these children learn best, and how you can help them process information.

Overhead Partners Plus Caregiver 7-2

Common Disabilities

- Learning Disability
- Mental Retardation
- Severe and Profound Disabilities
- Speech Impairment / Language Disorder
- Traumatic Brain Injury

Common Disabilities continued

Work your way through the disabilities, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

Mental Retardation (MR):

Children with MR show delays in cognitive and adaptive development. They often learn new skills at a slower rate.

Caregivers may need to take things at a slower pace with these children. Find out the age level at which children with MR are operating. For example, an eleven-year-old may have the cognitive skills of an eight-year-old. This information will help you plan activities for the children you are working with.

Orthopedic Impairment:

An orthopedic impairment affects the bones, muscles, and/or the way the body moves. There are many diagnoses included in this category, including cerebral palsy, spina bifida, and muscular dystrophy. Children with orthopedic impairments generally show motor delays.

Overhead Partners Plus Caregiver 7-2

Common Disabilities

- Learning Disability
- Mental Retardation
- Severe and Profound Disabilities
- Speech Impairment / Language Disorder
- Traumatic Brain Injury

Common Disabilities continued

Work your way through the disabilities, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

Depending on which parts of the body are affected, caregivers may need to help children with orthopedic impairments sit, stand, move from place to place, eat, communicate, and/or toilet.

Severe and Profound Disabilities:

Children with severe mental retardation are generally given the diagnosis of severe and profound disabilities. These children may have additional disabilities as well.

Children with this diagnosis generally need extensive help with self-care. Caregivers can learn from families about the best ways to work with them.

Speech Impairment/Language Disorders:

Children with speech impairments have difficulty producing sounds or have trouble with the way that their voices

Overhead Partners Plus Caregiver 7-2

Common Disabilities

- Learning Disability
- Mental Retardation
- Severe and Profound Disabilities
- Speech Impairment / Language Disorder
- Traumatic Brain Injury

Common Disabilities continued

Work your way through the disabilities, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

sound. A language disorder is diagnosed when a person has trouble using words appropriately or understanding what is said to him or her.

Caregivers will need to learn to understand and communicate with these children.

Traumatic Brain Injury (TBI):

TBI occurs when a person experiences a sharp blow to the head or the brain is damaged from an injury. Because different parts of the brain control different pieces of functioning, symptoms of TBI vary according to what part of the brain was injured.

Caregivers need to learn how the children they are working with are affected by TBI, and how they can help.

Overhead Partners Plus Caregiver 7-3

Common Disabilities

- Learning Disability
- Mental Retardation
- Severe and Profound Disabilities
- Speech Impairment / Language Disorder
- Traumatic Brain Injury

5
mins

Common Special Health Care Needs

Refer to overhead Partners Plus Caregiver Common Special Health Care Needs 7-3. The information in this section corresponds with Section 7 of the **Caregiver Manual**.

Work your way through the diagnoses, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

Working with children with special health care needs can be a different experience from working with children with other disabilities. Their concerns are generally more medical. Here again, we will briefly go through this list of special health concerns and talk about how caregivers might work with these children.

Allergies:

Some children need to avoid certain substances because they are allergic to them.

Caregivers will need to learn what those substances are, how they react when they come in contact with them, and what to do if they have a reaction.

Overhead Partners Plus Caregiver 7-2

Common Special Health Care Needs

- Allergies
- Asthma
- Cancer
- Congenital Heart Disease
- Cystic Fibrosis

Common Special Health Care Needs continued

Work your way through the diagnoses, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

Asthma:

Children who have asthma have difficulty breathing at times. Allergens generally trigger attacks.

Caregivers will need to learn how to know when a child is having an asthma attack and how to help him. In addition, caregivers should know what triggers attacks so they can plan activities that do not increase the risk of attack.

Cancer:

Cancer is a group of abnormal cells that multiplies uncontrollably. Sometimes, these cells can travel through the body and affect different body organs. Like TBI, cancer affects children differently depending on where these cells are growing.

Caregivers should plan for extra rest periods for children with cancer, who

Overhead Partners Plus Caregiver 7-3

Common Special Health Care Needs

- Allergies
- Asthma
- Cancer
- Congenital Heart Disease
- Cystic Fibrosis

Common Special Health Care Needs continued

Work your way through the diagnoses, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

may need to take medication or eat special diets. Ask families how to keep their children comfortable during care.

Congenital Heart Disease:

Children with congenital heart disease have trouble with their hearts from birth. Their hearts may not beat regularly or they are not structured the way they should be to do their jobs.

Caregivers of children with congenital heart disease should learn what activities are too stressful for children and what they enjoy doing. Caregivers may learn how to use a heart monitor, and how to respond to an emergency.

Cystic Fibrosis:

Cystic fibrosis is a condition that causes the lungs and other body organs to produce a lot of mucus. This mucus can build up in the child's body and affect the way that body organs function.

Overhead Partners Plus Caregiver 7-3

Common Special Health Care Needs

- Allergies
- Asthma
- Cancer
- Congenital Heart Disease
- Cystic Fibrosis

Common Special Health Care Needs continued

Work your way through the diagnoses, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

Refer to overhead Partners Plus Caregiver 7-4.

Caregivers for children with cystic fibrosis may feed them special diets and give them medication. They may also need to learn how to help these children clear their lungs of mucus.

Diabetes:

Children with diabetes do not process the sugars in food the way that other people do.

Caregivers may help children follow special diets, and give them medicine. In addition, caregivers may help children take blood tests to monitor their blood sugar. Finally, caregivers should watch children with diabetes for signs of high blood sugar or low blood sugar, and learn how to help them in these events.

Overhead Partners Plus Caregiver 7-4

Common Special Health Care Needs

- Diabetes
- HIV / AIDS
- Kidney Disease
- Seizure Disorders

Common Special Health Care Needs continued

Work your way through the diagnoses, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

HIV/AIDS:

HIV, the virus that causes AIDS, attacks the immune system. As a result, children with AIDS are vulnerable to infections. They may have other health conditions for which they will need special care.

Caregivers should learn from families how HIV/AIDS affects their children and how they can help.

Kidney Disease:

The kidneys clean waste from the blood. Children who have kidney disease have trouble with the way that their kidneys function.

Caregivers may need to take children with kidney disease to the hospital periodically to get the waste cleaned out of their blood. In addition, they may help children with special diets and medication routines.

Overhead Partners Plus Caregiver 7-4

Common Special Health Care Needs

- Diabetes
- HIV / AIDS
- Kidney Disease
- Seizure Disorders

Common Special Health Care Needs continued

Work your way through the diagnoses, emphasizing the points listed and using questions from the **Caregiver Manual** to illustrate how caregivers can learn to care for a child from the child's family.

Seizure Disorders:

Seizures occur when there is a sudden change in the way that the brain functions. As a result, the person with the seizure temporarily loses control over all or parts of her body. Epilepsy is one type of seizure disorder.

Caregivers will need to learn about the specific kind of seizure disorders affecting the children in their care. Many children with this diagnosis eat special diets and/or take medication. Caregivers will also learn how to monitor and keep children safe during seizures.

Overhead Partners Plus Caregiver 7-4

Common Special Health Care Needs

- Diabetes
- HIV / AIDS
- Kidney Disease
- Seizure Disorders

2
mins

Summary

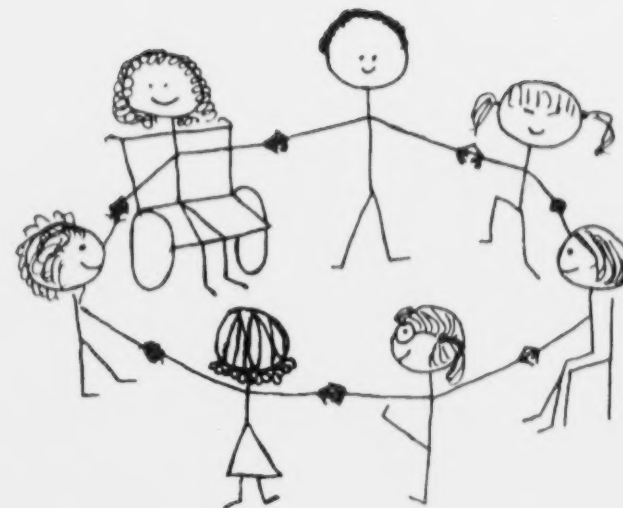
Ask the group for feedback.

Summarize the section.

Does anyone have any questions or comments about the information we just discussed? I encourage you to read through the information in this section in the **Caregiver Manual** very carefully for more information on special needs, how they affect development, questions to ask families about their children's conditions, and where to look for more information.

This information should be useful to you as you begin working with families with children with special needs. However, remember that families will give you the most information about their children and their children's conditions.

If you have questions, ask them to learn more. You need to feel comfortable with the children in your care.



Section 7—Children with Special Needs Suggested Overheads

DRAFT 10.99

Common Disabilities

- **Attention Deficit Disorder**
- **Autism**
- **Blindness / Visual Impairment**
- **Deafness / Hearing Impairment**
- **Emotional Disturbance**



Common Disabilities

- **Learning Disability**
- **Mental Retardation**
- **Orthopedic Impairment**
- **Severe and Profound Disabilities**
- **Speech Impairment / Language Disorder**
- **Traumatic Brain Injury**



Common Special Health Care Needs

- **Allergies**
- **Asthma**
- **Cancer**
- **Congenital Heart Disease**
- **Cystic Fibrosis**



Common Special Health Care Needs

- **Diabetes**
- **HIV/AIDS**
- **Kidney Disease**
- **Seizure Disorders**



10
mins

Section 8 Caregivers—Becoming a Caregiver

Objectives

- Understand how caregivers can become active members of a respite partnership in the Partners program
- Understand how caregivers can contribute to personalized training
- Know how to match with families for respite

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of Section 8, "Becoming a Caregiver," in the **Caregiver Manual**.

In this section, caregivers get information on becoming a Partners caregiver. Each community can choose how or if they distribute information on trained caregivers to families in the community. Please prepare for this section by becoming familiar with these procedures and developing necessary materials to communicate this to caregivers.

Prepare overhead transparencies of:

- Overhead Partners Plus Caregiver How I Learn Best 8-1
- Overhead Partners Plus Caregiver Training Ideas 8-2

Corresponding Sections

Please refer participants to Section 8, "Becoming a Caregiver" and "Final Activity" in the **Caregiver Manual**.

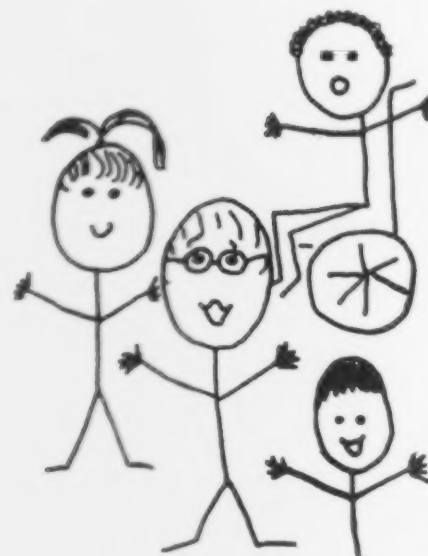
1
min

Introduction to Becoming a Caregiver

Introduce the concepts of the section.

Congratulations! You have almost finished Partners workshop! You have learned some basic information for providing respite care to children with special needs.

There are no overheads for this section.



6
mins

The Caregiver Role in the Partners Plus Model

Refer caregivers to Section 8, "Becoming a Caregiver," in the **Caregiver Manual**.

Introduce this section.

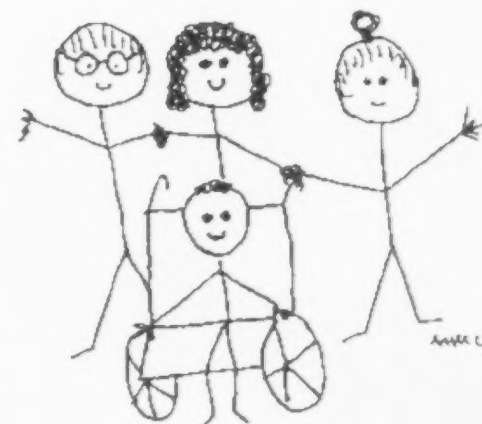
Ask participants to turn to "What Can I Contribute as a Respite Caregiver?" in Section 8.

After the workshop, the next step for interested caregivers is to match up with families for respite, and to go through personalized training with those families.

Partners is a family-centered model, and families have choices about what respite will look like for them. Likewise, caregivers also have choices about how they want to participate. The materials in this section will help you think about how you want to participate in interviewing, personalized training, and the respite experience.

Turn to Section 8, "What Can I Contribute as a Respite Caregiver?" in your manuals. The information on this page will help you think about why you want to be a respite caregiver. Families need committed caregivers. Think about whether this is work you will enjoy.

There are no overheads for this section.



The Caregiver Role in the Partners Plus Model continued

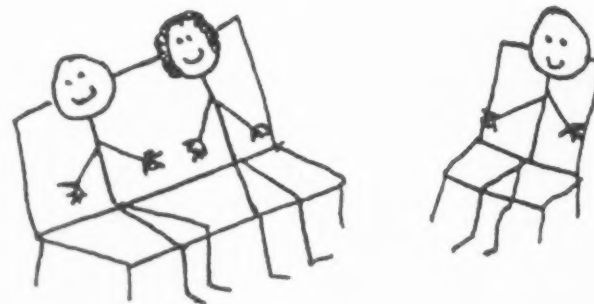
Discuss the sample interview questions.

The "Sample Interview Questions" on the next few pages of your **Caregiver Manuals** are the questions we suggest that families use in interviewing caregivers. Before an interview, take some time to consider these questions and your answers.

In this process of preparing yourself for the interview, think about what you want in this partnership, and why you think you will be a good respite caregiver.

Remember, the interview process is a time when you gather information from families just as they are gathering information about you. Take the time to think about some questions that you have for families before you interview with them.

There are no overheads for this section.



The Caregiver Role in the Partners Plus Model continued

Refer caregivers to "Developing a Personalized Training Plan" in their manuals.

Give an example to illustrate a "Personalized Training Plan."

If you and a family decide to work together, you will begin personalized training. As we have been talking, families have been learning a structure for training caregivers about their children. On the next pages, we have included that information for you, so you will have an idea of what training might look like.

We have suggested a four-step process for training. The family plans around the time of day their child will need care. In the first step, families identify their training goals. What will they need you to know for that time period? Then, they decide what training methods to use. How will they teach you what you need to know? In Step 3, families use resources to help you learn about their child. And finally, in Step 4, caregivers and families decide how they can evaluate the plan. How will you and families know when you have learned the goals, and that children, parents and caregivers are comfortable?

There are no overheads for this section.



The Caregiver Role in the Partners Plus Model continued

Refer caregivers to "Tips for Learning" in their manuals.

Caregivers should be active in their personalized training. There are many ways that you can be involved in planning and evaluating what and how you will learn.

Refer to overhead Partners Plus Caregiver How I Learn Best 8-1. This information is in Section 8 in the Caregiver Manual.

Different people learn best in different ways. Some people learn best when they read information. Others learn best when they hear it. Some people like pictures and diagrams. Families want to make sure that you are learning information in the best way possible. Think about how you learn best and share that information with families.

Overhead Partners Plus Caregiver 8-1

How I Learn Best

- Written Materials
- Audiotapes
- Videotapes
- Oral Instruction
- Demonstration, Feedback, Practice
- Other

The Caregiver Role in the Partners Plus Model continued

Refer to overhead Partners Plus Caregiver Training Ideas 8-2. This information is in Section 8 in the Caregiver Manual.

As you are trained by families, three things to keep in mind are:

Do I have the knowledge to care for this child?

Do I have the skills to care for this child?

Do I have the comfort to care for this child?

If you are feeling weak in any area, let the family know so they can provide additional training.

Conclude this section.

Throughout your respite relationship, share your thoughts, input, and concerns with families. If you are not comfortable in respite, you can be sure that the family you are working with wants to help you become comfortable with their child.

Overhead Partners Plus Caregiver 8-2

Training Ideas

- Knowledge
- Skills
- Comfort

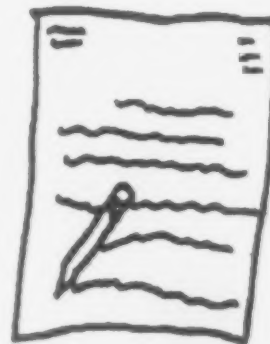
The Caregiver Role in the Partners Plus Model continued

Note: Use this time to tell caregivers how your program fosters caregiver/family partnerships. Many communities choose to create a directory of Partners caregivers to distribute to families looking for respite caregivers. If this is true of your community, use this time to tell caregivers how they can be included on that directory.

If any forms need to be completed before becoming a Partners caregiver, introduce them at this time for participants to complete.

Our community has created a directory of Partners caregivers to distribute to families looking for respite caregivers. If you would like to be included on that directory, please . . .

There are no overheads for this section.



2
mins

Summary

Ask the group for feedback.

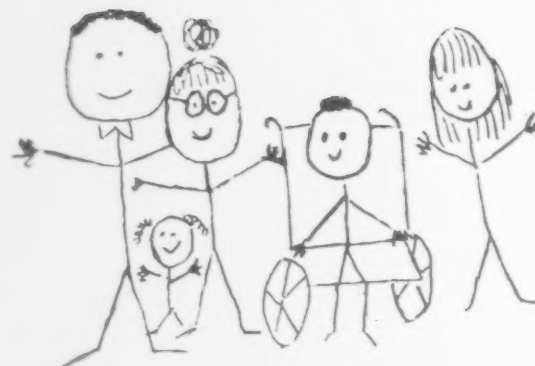
We've covered a lot of ground in a relatively short period of time. Does anyone have any questions on this section, or on anything we've covered in this breakout session?

Would anyone like to share some comments with the group about what we've discussed?

Conclude the section by stressing key ideas.

Remember that you are a partner in this respite relationship. Your opinion counts! Be sure to speak to families about your needs for training and support. Families do not expect that you will know a lot about their children without ever having met them and worked with them. Families tell us that, more than education and experience, the most important qualities in a respite caregiver are a desire and willingness to learn and a good attitude.

There are no overheads for this section.



Section 8—Becoming a Caregiver Suggested Overheads

DRAFT 10.99

473

How I Learn Best

- **Written Materials**
- **Audiotapes**
- **Oral Instruction**
- **Demonstration,**
- **Practice**
- **Other**

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**Partners Plus Workshop
Caregiver Manual Section 8**

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 8-1 C

Training Ideas

- Knowledge
- Skills
- Comfort

475

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**Partners Plus Workshop
Caregiver Manual Section 8**

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP 8-2 C

60
mins

Final Partners Workshop Activity—Using Daily Routines To Develop a Personalized Training Plan

Overview

Families and caregivers, who were separated for breakout sessions, should be reunited for this activity.

Objectives

- Learn more about developing personalized training plans
- Practice developing a personalized training plan using a child's daily routines

Preparations

Read the "Training Session Notes" carefully. Be sure you are familiar with the content, materials and design of the Final Activity.

In Section 8 Families, the trainer asked for a family volunteer to share information on her child's daily routine for this activity. Be prepared to use a child from your own experiences as an example in case no one

volunteers. You should know this child well, feel comfortable answering questions about the child, and be able to describe a routine in the child's day.

Prepare overhead transparencies of:

- Overhead Partners Plus Step 1 FA-1
- Overhead Partners Plus Step 2 FA-2
- Overhead Partners Plus Step 3 FA-3
- Overhead Partners Plus Step 4 FA-4
- Overhead Partners Plus Good Luck FA-5

Gather the following supplemental materials:

- If using overheads, markers for overheads
- If using flip charts, markers for flip charts

Preparing for the Final Activity continued

Prepare overhead transparencies of:

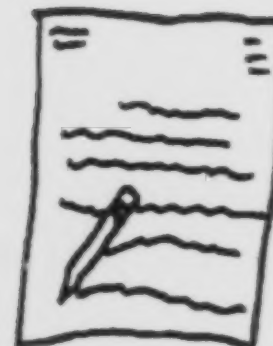
- Overhead Partners Plus 10-1 Step 1
- Overhead Partners Plus 10-2 Step 2
- Overhead Partners Plus 10-3 Step 3
- Overhead Partners Plus 10-4 Step 4

Gather the following supplemental materials:

- If using overheads, markers for overheads
- If using flip charts, markers for flip charts

Corresponding Sections

Please refer participants to Section 7 of the **Family Manual**, "Developing Your Personalized Training Plan," and Section 8 of the **Caregiver Manual**, "Becoming a Caregiver."



2
mins

Introduction to Using Daily Routines To Develop a Personalized Training Plan

Introduce the concepts of the Final Activity. Refer participants to the Personalized Training Plan in their manuals.

Note: If there were no volunteers from the Family Breakout Session, use a child you know as an example. Be certain to protect confidentiality!

We are glad to bring families and caregivers back together for this final activity. We will practice developing a personalized training plan. As we are going through this activity, think about what we talked about earlier in training: the importance of open and honest communication and the sharing of perspectives.

We are going to begin to build a personalized training plan for _____'s child,
_____ (name of the child).

We are going to use the steps outlined in your manuals to do that.

There are no overheads for this section.



20
mins

Using Daily Routines To Develop a Personalized Training Plan Activity

Ask the volunteer to tell the group about his or her child.

Before we begin, why don't you tell us a little about your child.

Great. What time do you want respite for your child? Be specific about the time of day and the day of the week. Having many times that you would like respite is fine, but for our discussion today just choose one.

Refer to overhead Partners Plus Step 1 FA-1.

Excellent. The first step to developing a personalized training plan is to identify your goals for training. What do you need the caregiver to know for this time with your child?

Overhead Partners Plus FA-1

Step 1

- Identify your training goals

Using Daily Routines To Develop a Personalized Training Plan Activity continued

Ask the volunteer to list the different goals for personalized training.

List all of the goals that she mentions on the overhead. Be sure that they are stated as specific goals. For example, instead of writing "feeding routine," write, "The caregiver will know how to feed (the child) lunch."

You may want to prompt the family member to ensure all goals are included.

Why don't you list the different goals you have for personalized training for a caregiver providing respite at _____ o'clock [the time chosen].

Does a caregiver need to know about feeding your child? Giving medication? Playing with your child?

There are generally many different training goals for one period of time. Not all of these goals will be taught to caregivers using the same activities. Let's choose one to discuss in a little more detail.

Overhead Partners Plus FA-1

Step 1

- Identify your training goals

Using Daily Routines To Develop a Personalized Training Plan Activity continued

Have the volunteer choose a goal that she feels comfortable describing to the group.

Refer to the overhead Partners Plus Step 2 FA-2.

Encourage the volunteer to share her ideas. Again, write them on the overhead. You may need to prompt her.

Ask other members of the group to get involved. Add additional ideas to the overhead.

Which goal would you feel most comfortable exploring in detail?

Fine. The second step is to decide what methods you could use to achieve your goal. How are you going to teach a caregiver this goal?

How did you learn that routine? What about the teaching activities in the manual?

What about the rest of you? How would you want to learn? Would any of the listed ideas not work for you? Do you learn better in a different way? This is the perfect time to share their ideas and opinions openly.

Overhead Partners Plus FA-2

Step 2

- List your training methods

Using Daily Routines To Develop a Personalized Training Plan Activity continued

At this point in the discussion, families and caregivers may ask the family specific questions about the child and the routine. Question and answer is a valuable learning activity.

Refer to overhead Partners Plus Step 3 FA-3. Ask the volunteer for specific instructions for the caregiver. List resources on the overhead.

If she does not mention anything, describe some possible resources families may use for caregivers.

Now I'd like each of you to pretend that you are the caregiver for this family: do you need more information or details from the family?

Many different methods can be used. Families and caregivers can decide which would work best for them, and in what order they should be used.

Let's move on to step 3: The third step is to use resources to help train your caregiver. Is there anything that you can give a caregiver to help him learn about your child or this routine?

Families do not always have resources for each goal. Some possible resources may be . . .

Overhead Partners Plus FA-3

Step 3

- Use resources to help train your caregiver

Using Daily Routines To Develop a Personalized Training Plan Activity continued

Could you draw or write anything for the caregiver that might be useful? You can do it right on the overhead sheet.

Refer to overhead Partners Plus Step 4 FA-4.

Write responses on the overhead.

The final step is evaluation. How will you know when the caregiver has reached the goal and the parents, caregiver, and child all feel comfortable enough to be in respite?

Let's let our volunteer think about that question for a minute. Do you have any ideas for evaluation?

If the volunteer does not have evaluation ideas, prompt her.

Will you know that the caregiver has learned the feeding routine when you watch him go through it? Will you ask the caregiver questions to see if he knows the correct answers?

Overhead Partners Plus FA-4

Step 4

- Evaluate your training plan

Using Daily Routines To Develop a Personalized Training Plan Activity continued

Ask caregivers for their input. Add their ideas to the list as well.

What about the caregivers? How will you know when you have reached the family's goals? It is important that caregivers feel comfortable in respite, just as it is important that families feel comfortable leaving their children. When will caregivers feel prepared to do a routine on their own? Do you want families to watch you go through the routine? Do you want to be observed more than once?

Overhead Partners Plus FA-4

Step 4

- Evaluate your training plan

33
mins

Summary

Ask the group for feedback.

Thank you for volunteering to share your experiences with the rest of the group. Does anyone have any questions about this section?

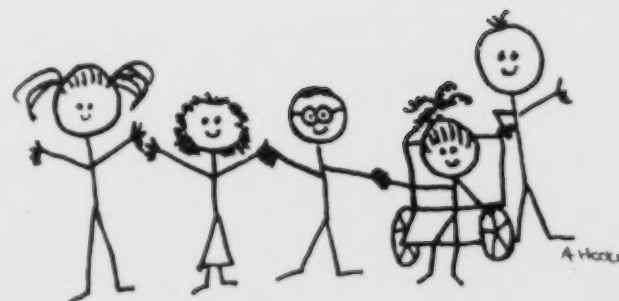
There are no overheads for this section.

Would anyone like to share some comments with the group about what we've discussed?

Conclude the final activity.

After planning for the goal we discussed is completed, the family would go back and repeat this planning process for every goal listed in Step 1.

Families and caregivers who work together through this process will have plans not just personalized to the child and family, but to all three members of the partnership—the family, the caregiver, and the child. These plans are most effective when each personalized training plan is specific to a family-caregiver match. Building these plans together is another way to strengthen the family-caregiver relationship.



Summary continued

Conclude the workshop.

Special Note: Pass out the evaluation measures to families and caregivers. Master copies of these are included with the *Supplemental Materials* in the Welcome to the Partners Workshop section.

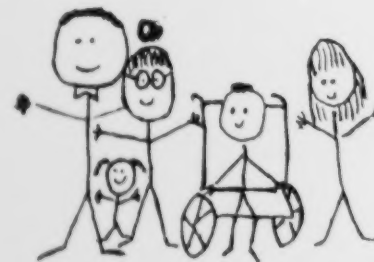
Pass out evaluation measures and tell participants how helpful their comments are. Distribute copies of "What Did You Think About the Training?" to the group. Distribute copies of "Caregiver Knowledge Measure" and "Caregiver Comfort Measure" to the caregivers in the group.

We hope that you will use the information you have learned here as you build respite relationships in the future. Children only have adults to support them, care for them, and advocate for them. When adults—families and caregivers—work together closely and develop strong relationships, children reap the rewards.

Thank you for coming today! Before you leave, we'd like you to take a moment to complete some evaluation measures for the workshop. These measures will let us know whether we are meeting objectives in training, what we are doing well, and what needs additional work. Your comments are very helpful in our efforts to improve training.

Overhead Partners Plus FA-5

Good Luck in Your
Respite Partnerships!



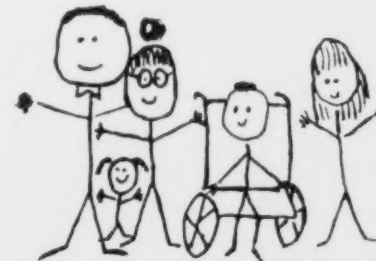
Summary continued

Evaluation measures to be distributed at the workshop are included as supplemental materials at the end of this section. Refer to the **Community Planning Manual** for a complete set of evaluation measures.

Administer evaluation measures after concluding the session. Leave 30 minutes for people to complete their evaluations.

Overhead Partners Plus FA-5

Good Luck in Your
Respite Partnerships!



**Final Activity—Using Daily Routines
To Develop a Personalized Training Plan
Suggested Overheads**

DRAFT 10.99

Step 1

- **Identify your training goals.**

DRAFT 10.99



Partners Plus Workshop
Family and Caregiver Manuals Final Activity
Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP FA-1

Step 2

- **List your training methods.**

DRAFT 10.99



Partners Plus Workshop
Family and Caregiver Manuals Final Activity
Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP FA-2

Step 3

- **Use resources to help train your caregiver.**

DRAFT 10.99



Partners Plus Workshop
Family and Caregiver Manuals Final Activity
Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP FA-3

Step 4

- **Evaluate your training plan.**

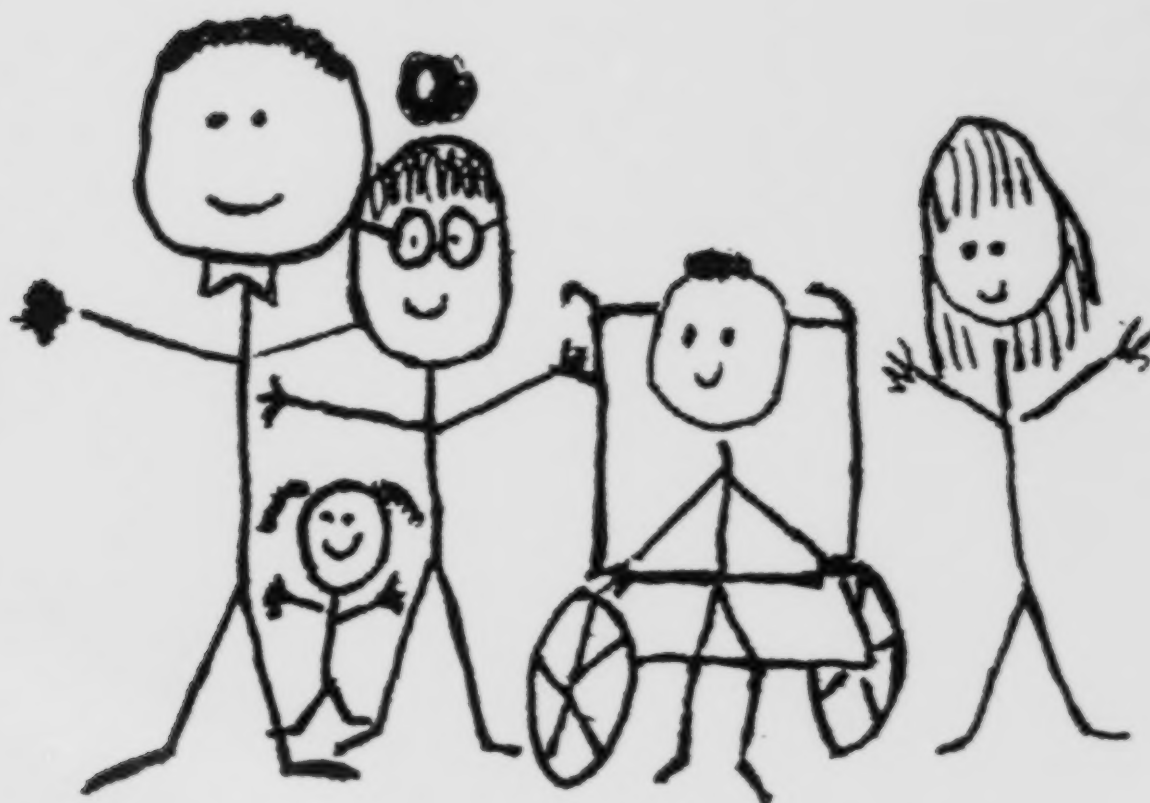
DRAFT 10.99



Partners Plus Workshop
Family and Caregiver Manuals Final Activity
Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP FA-4

Good Luck in Your Respite Partnerships!



DRAFT 10.99



Partners Plus Workshop

Family and Caregiver Manuals Final Activity

Child Development Resources, P.O. Box 280, Norge, Virginia 23127

PP FA-5

**Final Partners Workshop Activity—Using
Daily Routines To Develop a Personalized
Training Plan Supplemental Materials**

DRAFT 10.99

What Did You Think About the Workshop?

Name: _____ Date: _____

Presenter(s): _____

1. What I liked about the workshop...

2. How Did We Do? The information presented was:

_____ easy to understand

_____ difficult to understand because...

3. The information presented was:

_____ useful

_____ not useful because...

4. The overall quality of the workshop was: 1 2 3 4 5
Very Poor Very Good
5. Were the workshop materials helpful? 1 2 3 4 5
Not at All Very
6. Was the information presented appropriate for your needs? 1 2 3 4 5
Not at All Very
7. Was there enough chance for questions and discussion? 1 2 3 4 5
Not at All Very

8. I gained knowledge about...

9. Suggestions I would like to offer for improving the workshop...

10. I think what I'll remember most was...

11. Please share any additional comments:

Partners Plus Caregiver Comfort Scale Post Evaluation

Caregiver's Name: _____ Date: _____

Please circle the number that best describes how comfortable you feel in working with children with special needs.

How comfortable are you:

	Uncomfortable		Somewhat Uncomfortable		Very Comfortable
1. Providing care for a child with special needs.	1	2	3	4	5
2. Planning activities that a child with special needs can enjoy.	1	2	3	4	5
3. Meeting the routine health care needs of a child with special needs.	1	2	3	4	5
4. Feeding a child with special needs.	1	2	3	4	5
5. Talking with families of children with disabilities about their child and their child's strengths and needs.	1	2	3	4	5
6. Talking to other people about any concerns they may have about children with special needs in your care.	1	2	3	4	5
7. Identifying resources and getting help you may need in caring for children with special needs.	1	2	3	4	5

Thank You !

Partners Plus Caregiver Knowledge Post Evaluation

Name: _____ Date: _____

This survey is designed to gather information about your experience and knowledge of caring for children with disabilities or special needs.

Read each statement and circle the single best answer.

1. Early intervention services are available to children with disabilities who are
 - a. Birth to three years old
 - b. In public schools
 - c. Three to five years old
 - d. I don't know
2. Children who receive early intervention special education services must
 - a. Get therapy
 - b. Go to a classroom program
 - c. Have an individual plan
 - d. I don't know
3. All children with special needs receive education through
 - a. MCH
 - b. CHIP
 - c. IDEA
 - d. I don't know
4. Which of these diagnoses tells you that a child has a special health care need?
 - a. Autism
 - b. Cystic Fibrosis
 - c. Mental retardation
 - d. I don't know
5. Providing good respite care for a child with a disability depends heavily on
 - a. Desire/attitude of caregivers
 - b. Educational level of the caregiver
 - c. A child's disability
 - d. I don't know
6. When caring for children with disabilities in their homes, it is necessary to
 - a. Learn about their daily household routines
 - b. Change things to suit your way of providing care
 - c. Ignore the way the family trained you to take care of the child
 - d. I don't know

7. A key to a successful respite care program for families is
 - a. Providing each family with many caregivers
 - b. Allowing each family to train their own caregivers
 - c. To start more respite agencies
 - d. I don't know

8. It is most important for respite caregivers to
 - a. Understand child development
 - b. Know the needs of the child or children in their care
 - c. Have a degree or certification
 - d. I don't know

9. The term "cognitive development" is used to describe how a child
 - a. Relates to others
 - b. Sits and grasps toys
 - c. Thinks and solves problems
 - d. I don't know

10. If caregivers have questions or concerns about a child's special needs, they should
 - a. Discuss their concerns with the child's parent(s) or guardian
 - b. Call the local special education program
 - c. Not do anything because if they are wrong it would upset the child's parents
 - d. I don't know

Thank You!



Resources

Overview

This section includes just a few of the many resources available to training programs. Check your local library, internet, and video stores for resources to help trainers become more effective.

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References on Adult Learning

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- Rossman, M.H., Fisk, E.C., and Roehl, J.E. (1984). *Teaching and Learning Basic Skills: A Guide for Adult Basic Education and Developmental Education Programs* (New York: Teachers College Pr.).

Training Resources

Creative Training Techniques Newsletter
Lakewood Publications
50 S. 9th St.
Minneapolis, MN 55402

(800) 707-7749

<http://www.trainingsupersite.com/publications>

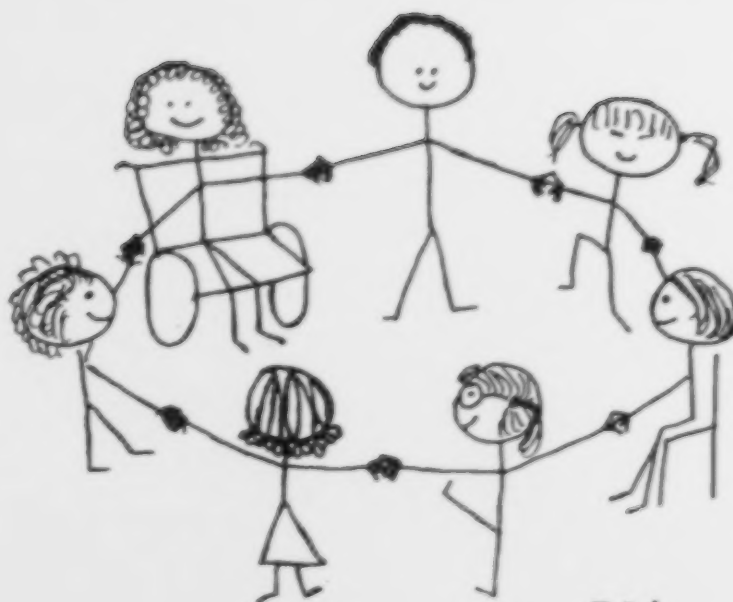


Forms for Sharing Information

Information Worksheets

There are a variety of forms available in this section for families to use in sharing important information with caregivers. Families can use these forms as needed. Some forms provide information specific to the child with special needs and other forms are specific to the needs of siblings also in care. Some forms provide space to include other family and household information. Emergency, health, and safety information sheets and checklists are helpful for caregivers to have.

Master copies of all forms and worksheets are included in this section. Families can make copies of forms that several caregivers may need. Families may also keep blank copies and use them when changes occur or new information becomes available.



520

521

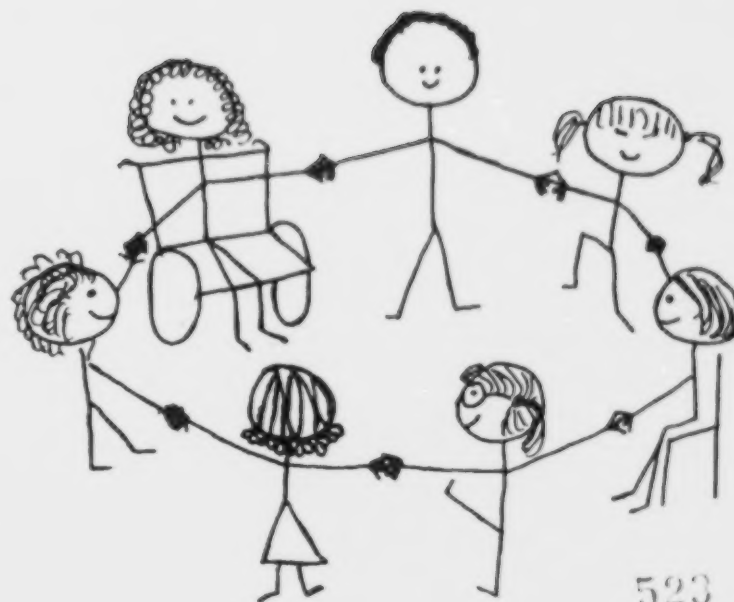


Forms for Sharing Information

Information Worksheets

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Essential Information

General Information

Child's Name: _____ Nickname: _____

Address: _____

Phone: _____ Allergies: _____

Age: _____ D.O.B. _____ Height: _____ Weight: _____

Child diagnosis or description of special needs: _____

Health Insurance: _____ I.D. Number: _____

You can reach me at _____

If you cannot contact me, please call:

_____ Phone: _____

Medication

Name of medication: _____

Purpose for medication: _____

Time to be given: _____ Dosage: _____

Pharmacy: _____ Phone: _____

Comments: _____



Essential Information (continued)

Food

Allergies: _____

Cannot have: _____

Acceptable snacks: _____

Meals: _____

Daily Schedule

AM: _____

PM: _____

Nap Time: _____



Health and Medical Information

Child's Name: _____ Date of Birth: _____

Current Health Problems / Needs: _____

Allergies (if any): _____

Child's Physician: _____

Address: _____

Phone: _____

Name and Number of Medical Insurance: _____

Authorization for Emergency Medical Care

_____ has permission to obtain immediate medical care for my child if any emergency occurs when the parent or guardian cannot be located. I understand the child's physician will be contacted if available.

Parent or Guardian: _____ Date: _____



Important Phone Numbers

Mother's Work: _____

Father's Work: _____

Police/Emergency: _____

Fire/Emergency: _____

Poison Control: _____

Doctor's Office: _____

Pharmacy: _____

Hospital: _____

Dentist: _____

Neighbor/Friend: _____

Neighbor/Friend: _____

Relative: _____

Relative: _____

Gas Company: _____

Electric Company: _____

Phone Company: _____

Apartment Manager: _____

Veterinarian: _____

Other: _____



About My Child

Child's Name: _____ Date: _____

What I would like to tell you about my child: _____

Favorite toys or playthings: _____

Special routines (a good-bye hug, snack after school, story for bedtime, etc.)

my child enjoys: _____

Special things (blanket, a pacifier, stuffed animal, etc.) that my child enjoys:

Things that scare my child: _____



Things that quiet or comfort my child: _____

Special things my child does: _____

Activities my child likes: _____

Activities my child dislikes: _____

Personality or behavior style (such as active, quiet, silly, serious): _____

Things that are easy for my child: _____

Things that are hard for my child: _____

Special names or words for people or things that my child understands/uses:

Other special information or concerns: _____

531



About Our Family

The people in our family are: _____

Some things our family does together: _____

Special things each member of my family does alone or with someone else:

Things we would like to do if we had respite: _____



About Sisters and Brothers

General Information

Brother/Sister's Name: _____ Nickname: _____

Age: _____ D.O.B.: _____ Height: _____ Weight: _____

Allergies: _____

Important health or developmental history: _____

Medications

Name of medication: _____

Purpose for medication: _____

Time to be given: _____ Dosage: _____

Pharmacy: _____ Phone: _____

Prescribing Doctor: _____

Doctor's Phone: _____

Let me tell you about _____



Health and Safety Checklist

Our caregiver is certified in:

- ☐ infant/child CPR
- ☐ first aid

Our caregiver knows where we keep our:

- ☐ medical treatment release forms
- ☐ medical insurance information
- ☐ first-aid kit and book
- ☐ sunscreen

We have provided our caregiver individualized training on:

- ☐ emergency plans
 - ☐ what we would consider an emergency for our child
 - ☐ what we would like our caregiver to do in case of an emergency
 - ☐ where we keep emergency phone numbers
- ☐ fire safety
 - ☐ location of and how to use the fire extinguisher
 - ☐ our fire evacuation plan
 - ☐ location of smoke detector
- ☐ poison safety
 - ☐ where we keep the Poison Control Center phone number
 - ☐ where we keep the Syrup of Ipecac
- ☐ kitchen safety (i.e., stove, appliances, pots on the stove, etc.)
 - ☐ first aid for burns



We have provided our caregiver individualized training on:

- ☐ hand washing for caregivers and children after toileting and outside time and before food preparation
- ☐ medication administration
- ☐ our smoking policy
- ☐ diaper/toileting routine and diaper disposal
- ☐ toy safety (e.g., balloons might suffocate small children, young children might choke on small toys or toys with small parts)
- ☐ use of medical equipment
- ☐ crib/bed safety
 - ☐ young children should sleep on their backs
 - ☐ the side rail of a crib should be latched when the child is asleep
 - ☐ caregivers should check on sleeping children
 - ☐ bottles should be held and not propped for young children
- ☐ positioning, exercises, and therapeutic activities
- ☐ car safety
 - ☐ car seats are available and adjusted for our child
 - ☐ correct use of a car seat
 - ☐ child should always be in a car seat or fastened seat belt when the car moving
- ☐ my child's allergies
 - ☐ medical care if my child is exposed to allergens
- ☐ safety in the home
 - ☐ electrical outlets are covered
 - ☐ hot water heater adjusted to 120 degrees or lower
 - ☐ guns are unloaded and locked in a cabinet
 - ☐ bullets are locked in cabinets separate from guns
- ☐ medications, poisonous chemicals, and liquor are kept out of the reach of children
- ☐ rubber mats or nonslip surfaces are in showers or tubs children will use

Step 1: Identify training goals.

What do you want your caregiver to learn about your child and family routines?

I want my caregiver to learn about these routines:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____



Step 2: List training methods.

What methods will you use to teach your caregivers?

In order to reach these goals I will use the following methods:

Goal 1: _____

Methods:

1. _____

2. _____

3. _____

Goal 2: _____

Methods:

1. _____

2. _____

3. _____



Goal 3: _____

Methods:

1. _____

2. _____

3. _____

Goal 4: _____

Methods:

1. _____

2. _____

3. _____

Goal 5: _____

Methods:

1. _____

2. _____

3. _____

Step 3:

Use resources to help train your caregiver.

What information will you use to help your caregiver learn?

These are the resources I would like to use:

- ☐ books
- ☐ handouts
- ☐ videotapes
- ☐ audiotapes
- ☐ computer search
- ☐ I develop resources
- ☐ other (please describe)



Step 4: Evaluation

How will you and your caregiver know when a specific skill or routine has been learned?

I will know a specific skill or routine has been learned when we accomplish the following:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____



Personalized Training Plan

Child's Name: _____ Date: _____

Routine: _____

Time of Day: _____

Step 1: Training Goal _____

Step 2: Training Methods _____

Step 3: Resources _____

Step 4: Evaluation _____



Respite Caregiver Profile

Date: _____

Personal:

Name: _____ SS#: _____

Address: _____

Home Telephone: _____ Work Telephone: _____

In case of emergency, notify: _____

Relationship: _____

Home Telephone: _____ Work Telephone: _____

Experience:

Describe experience you have had with children (including your own). _____

Have you ever provided care for children with disabilities?

☐ Yes ☐ No

If yes, please list your experiences: _____



Respite Caregiver Profile, continued

Have you had any courses in early childhood, child development, or child health?

☐ Yes ☐ No

Are you certified in Red Cross First Aid?

☐ Yes ☐ No Date of Expiration _____

Are you certified in Infant/Child CPR?

☐ Yes ☐ No Date of Expiration _____

Do you have a valid driver's license?

☐ Yes ☐ No Date of Expiration _____

Education:

I have completed:

High School _____ Some College _____

College _____ Graduate School _____

Degree or Major (specify): _____

Other training/education: _____

Employment:

Current Employer: _____

Position: _____

Respite Caregiver Profile, continued

Interests: (Check all that apply)

I am willing to care for children ages

birth - 2 _____ 2 - 5 _____ 5 - 8 _____ over 8 _____

I am willing to provide care (check all that apply):

- | | |
|--|------------------------------------|
| ☐ at my home | ☐ weekdays |
| ☐ at child's home | ☐ weekends |
| ☐ during the day | ☐ overnight |
| ☐ during evenings | ☐ anytime |

When I provide care, I will care for:

- ☐ only the child with disabilities
- ☐ the child with disabilities plus siblings
- ☐ the child with disabilities and other children in my care
- ☐ the child with disabilities and my own child/children

I would prefer to provide care:

- ☐ as a volunteer
- ☐ in exchange for a service (i.e., transportation, lawn care, meals, etc.)
- ☐ for an hourly rate of \$ _____
- ☐ for a negotiable hourly rate

How far are you willing to travel to provide care? (Check all that apply.)

- | | |
|---|-------------------------------------|
| ☐ Williamsburg/James City County | ☐ Hampton |
| ☐ York County | ☐ Poquoson |
| ☐ Newport News | ☐ Gloucester |



Respite Caregiver Profile, continued

References:

Please provide the names, addresses, and phone numbers of two persons we may contact who have known you for more than 1 year (excluding relatives or roommates).

Name: _____ Phone: _____

Address: _____

Name: _____ Phone: _____

Address: _____

I am most interested in providing respite care because _____

Thank You!



Reference Check

Date: _____

Name of Potential Caregiver: _____

Name of Reference: _____ Phone: _____

1. How do you know _____ ?
(put name of potential caregiver here.)

2. How long have you known _____ ?

3. What words best describe _____ ?

4. How would you best describe how _____
relates to children?

5. Describe what you think are _____'s strong
points in working with children with special needs and their families?

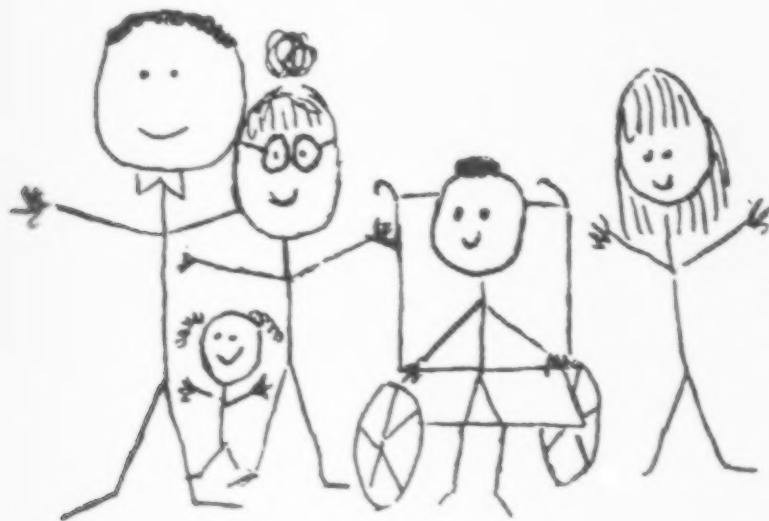
6. Are there any other comments about _____
you would like to make?

BEST COPY AVAILABLE :



Partners *Plus*

Community Planning Manual



Families and Caregivers in Partnerships

Child Development Resources

DRAFT 10.99

Partners Plus

Families and Caregivers in Partnerships: Community Planning Manual

Developed By

Amanda C. Hooke, M.S.W.

Lisa L. Ownby, M.S.W.

Dee Wylie Moore, B.S.

Corinne W. Garland, M.Ed.

Adrienne Frank, O.T.R.

The Community Planning Manual is part of a series of resources in the Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care. The rest of the series includes the Trainer's Workshop, Family, and Caregiver Manuals, created by Child Development Resources.



DRAFT 10.99



Revised from the original

PARTners Plus: Parents as Respite Trainers Community Planning Manual

Authors: Corinne W. Garland, Barbara A. Kniest, Karen S. McKinney, Dee W. Moore, and Nancy Tyree (1995)

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A Word About Funding

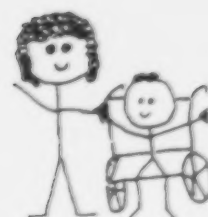
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Child Development Resources
Post Office Box 280
Norge, VA 23127-0280
Phone (757) 566-3300 / Fax (757) 566-8977

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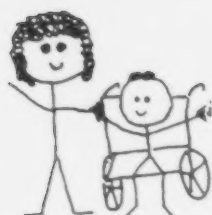
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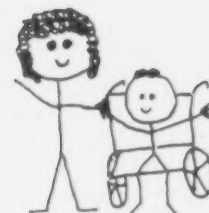
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Community Planning Manual

introduction

Partners Respite Model

The Partners Model of Respite Care...

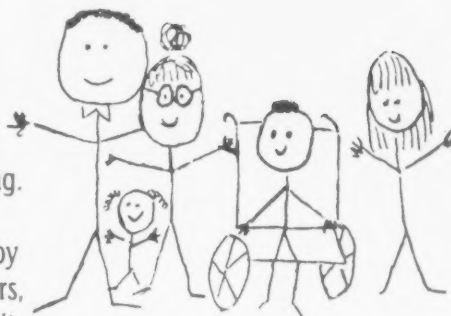
Helps families of children with special needs find and train their own respite caregivers.

Through training and support, families and caregivers build long-lasting, successful respite relationships.

Introduction

Like all families, families of children with special needs want and need time away from the demands of parenting. **Respite—or temporary child care for children with disabilities or chronic illness**—gives families time to enjoy an evening out by themselves, with other family members, or with friends. However, for these families, finding respite care is not as simple as calling a neighborhood babysitter. These families need caregivers who understand their children's special needs.

When the staff at Child Development Resources (CDR) spoke with families about what they wanted in a respite program, the message was clear. Families wanted to choose and train their own respite caregivers. They wanted affordable care that was as simple to schedule as calling the neighborhood babysitter. And, families wanted caregivers who were trained to provide care.



A Brief Partners History

In response to families and with support from the Virginia Institute for Developmental Disabilities (VIDD), a University Affiliated Program at Virginia Commonwealth University in Richmond, Virginia, CDR developed a pilot project that was low-cost, family-directed respite care called **PARTners: Parents As Respite Trainers**.

CDR was awarded, in 1994, a three-year grant from the U.S. Department of Education, Office of Special Education Programs (OSEP), Early Education Program for Children with Disabilities (EEPCD), to build on the pilot and to develop a model of respite that could be replicated in other communities. The project, **Partners Plus: Families and Caregivers in Partnerships**, provides a model for families to use in finding and training respite caregivers. This model encourages families to use available, **natural** family and **community** supports to meet their respite needs.

Within this model, Partners broadly defines the terms *respite* and *caregiver*. For example, respite can take place in a family's home, a caregiver's home, or in before and after school, recreation, camp, or other children's program. A caregiver can be any individual who *provides respite care* to a child with special needs or *includes* a child with special needs within an existing community program.

Partners Plus provided training to more than 200 families and caregivers in a five-city, three-county area of eastern Virginia. Partners usually conducted the six hour Partners Plus workshop for families and caregivers in one day. Sometimes when it was more convenient for a group, Partners conducted the workshop in two parts on separate days. This flexibility ensured that Partners adapted training

A Brief Partners History

to fit the schedules of families and caregivers who are generally most receptive to training during nontraditional hours such as evenings and Saturdays. Families attending the workshop learned to provide their own caregivers with personalized training based on their children's daily routines. Families either came to the workshop with their own caregivers, met caregivers through the workshop, or through other project activities.

The Partners Project resulted in the development of four manuals designed to help communities, trainers, families, and caregivers use the Partners model. The **Community Planning Manual** is one of four in a series of manuals that Partners has conveniently packaged together in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**. Besides the set of manuals contained in the guide, you can purchase the **Family and Caregiver Manuals** separately from the Partners Plus program through CDR.

Child Development Resources
Post Office Box 280
Norge, VA 23127-0280
Phone (757) 566-3300
Fax (757) 566-8977
Email ppcdr@tni.net



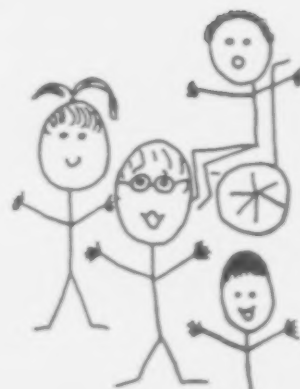
Partners Model: 5 Steps

The Partners Model: A New Model of Respite Care

Partners programs provide group training and continuing support to families and potential caregivers. The Partners model contains five steps:

The Five Steps of the Partners Model

- 1. Recruit Families and Caregivers*
- 2. Conduct Partners Workshop*
- 3. Help Families Choose Caregivers*
- 4. Support Families as they Train their Own Caregivers*
- 5. Provide Continuing Support*



Step 1: Recruit Families

First, programs **recruit** families and potential caregivers to participate in Partners. Community awareness activities invite potential participants to a Partners workshop. Information about the workshop and the Partners program is distributed through parent groups, newspapers, radio, flyers, word of mouth, etc.



Partners Model: 5 Steps

Step 2: Conduct Partners Workshop

Next, programs *conduct the Partners workshop*. During the six-hour workshop, families learn how to find, screen, and interview caregivers for their children. In addition, they learn to structure training for their own caregivers based on the specific needs and daily routines of their individual children. Caregivers learn basic information about caring for children with special needs. During the workshop, caregivers are preparing to be active in their work with families, reflecting on their motivations for becoming respite caregivers and identifying their own learning needs for personalized training. Partners **Family** and **Caregiver Manuals** provide participants with useful resources to actively engage in during the workshop and to use as resources as they move through the next steps of the model.

Step 3: Families Choose Caregivers

After the workshop, Partners programs provide continuing support as *families choose caregivers*. Families frequently identify respite caregivers within their own circles of natural support. If families are unable to identify their own caregivers, Partners will assist by providing social and educational events that will help families and caregivers meet. During interviews, families and caregivers negotiate how respite occurs. Respite may be in-home or out-of-home and reimbursement for care can be flexible. Care may be provided for a fee, voluntarily, or in exchange for another service, such as yard work.



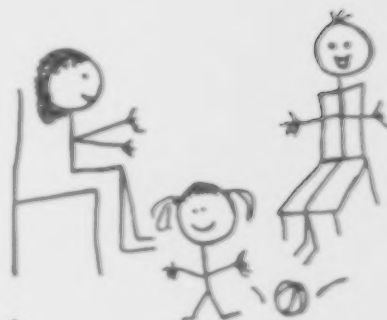
Partners Model: 5 Steps

Step 4: Families Train Caregivers

Once families and caregivers decide to work together, *families train their own caregivers*. This "personalized training," discussed during the workshop, is organized by families with help from Partners staff if needed. Families decide what routines caregivers need to learn and work with caregivers to determine how training will occur, thus forming true partnerships necessary for successful respite.

Step 5: Provide Continuing Support

As families and caregivers work together to develop a personalized respite training, the community Partners program *offers continuing support*, information and guidance. The Partners program is available to support families and caregivers in various ways as they begin their respite relationship. Partners staff members respond to requests for help and support from both families and caregivers. For example, Partners may help families and caregivers with screening, interviewing, developing personalized training plans, and providing educational opportunities.



Partners Replication Process

Partners Plus Replication Process

The Partners Plus Community Planning Manual, contained in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**, helps communities use the Partners model of respite care. Each community interested in model replication develops a plan for collaboration among agencies, organizations, and individuals in order to implement the model. Community resources and supports are needed to sustain the model, to create a home for the program, and to ensure continuation.

The community replication process includes four major steps:

- 1. Identifying the site for replication*
- 2. Planning for replication*
- 3. Implementing the model*
- 4. Evaluating the model*

The Partners Plus Community Planning Manual is a step-by-step guide for the replication process outlined in the flowchart on page xiv.

Your community will be a good candidate for replication if you have the following:

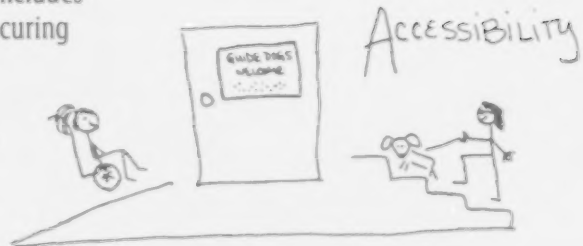
- support from agencies that provide, or are involved with, respite services



Partners Replication Process

- knowledge of current respite funding to support families without financial resources
- support and commitment from local early intervention programs, mental health or mental retardation programs, and/or family support programs

Each community needs to develop a *plan for replication*. Awareness activities aimed at a broad array of agencies, organizations, and individuals help strengthen community support. The creation of an advisory committee brings expertise and resources that will ensure a quality program. The replication plan includes finding a home for the program and securing staff responsible for implementing the program. Formal or informal interagency agreements and perhaps grant proposals may be necessary for community replication.



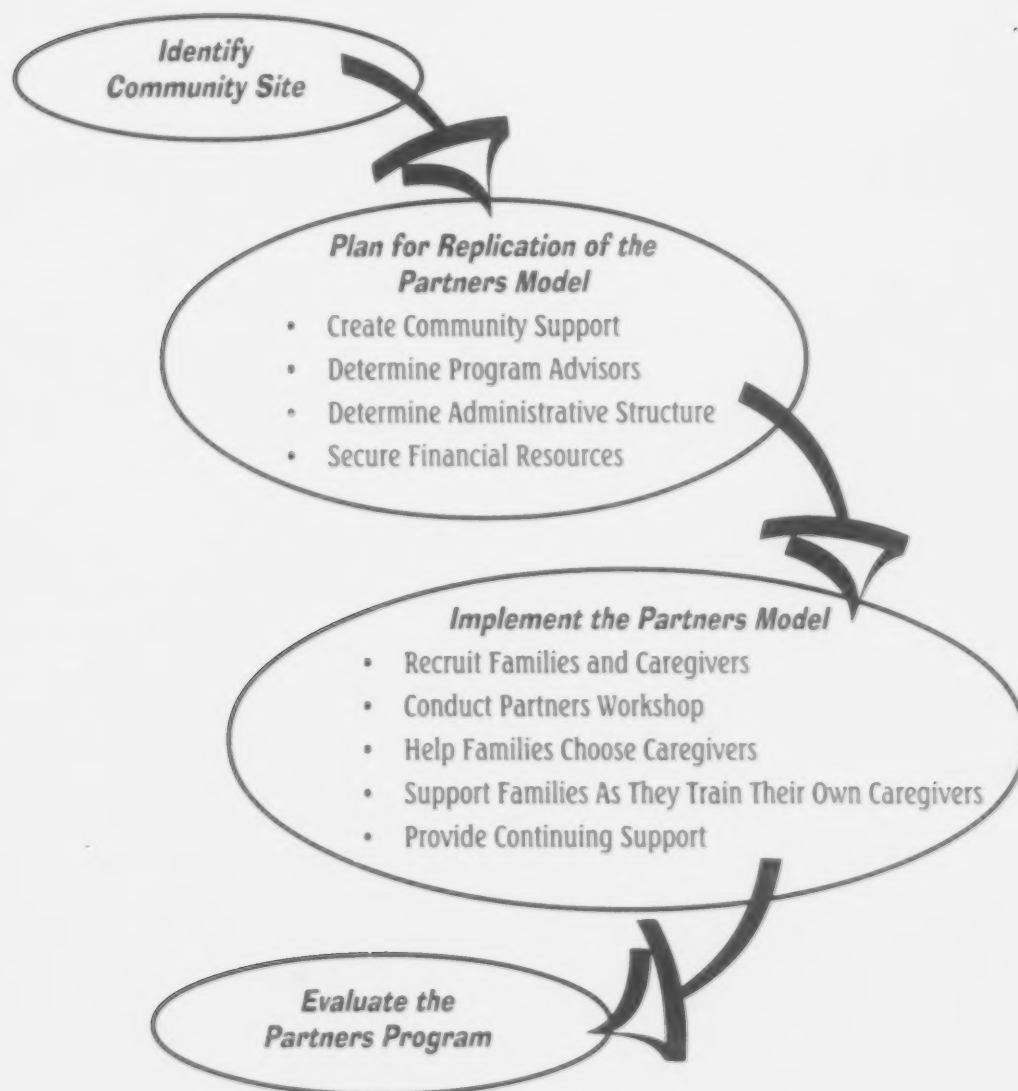
The **Community Planning Manual** provides strategies and materials to help communities develop and *implement* the respite care program. The **Trainer's Workshop Manual**, accompanying the **Community Planning Manual**, includes agendas, overheads, and suggestions for what to say during the Partners workshop. There are also suggestions for the kinds of resources that are needed by families and caregivers in order to foster and maintain long-term relationships.

Communities that replicate the Partners model gather information from families and caregivers to *evaluate* the quality and usefulness of training and support.



Partners in your Community

Partners Community Implementation Process



Partners Plus Manuals

Partners Plus Manuals

There are four manuals in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care** that support the Partners Plus replication process:

1. The **Family Manual**
2. The **Caregiver Manual**
3. The **Community Planning Manual**, and
4. The **Trainer's Workshop Manual**.

The **Family** and **Caregiver Manuals** are used in the Partners workshop for families and caregivers. These manuals include resources that families and caregivers can continue to use as they develop partnerships for respite care for children with special needs. The **Community Planning Manual** helps communities develop a community-based, family-centered respite system. The **Trainer's Workshop Manual** contains overheads, forms, and "helpful hints" for conducting Partners workshops.

The **Family Manual** is easy to follow and guides families in choosing and training their own respite caregivers. Families use their children's daily routines to develop training plans for caregivers. The manual includes information about respite, communication, building partnerships, selecting caregivers, and developing personalized training. There are worksheets, resources, and forms that can be duplicated for future use.



Partners Plus Manuals

The **Caregiver Manual** provides caregivers with basic information on caring for young children with disabilities and supporting families. This manual includes information about respite, communication, building partnerships, disabilities awareness, child development, children with special needs, and personalized training with families.

The **Community Planning Manual** provides communities with a step-by-step guide to replication of the Partners model. By following each step, communities and families can work together to develop respite care programs. The manual contains forms and materials to assist with replication of the model.

The **Trainer's Workshop Manual**, used in conjunction with the **Community Planning Manual**, helps community trainers to conduct the six-hour Partners workshop for families and caregivers.



1

Section 1

Planning your
Partners program

The Replication Process

Planning Your Partners Program: The Replication Process

This manual, the **Community Planning Manual**, helps communities use the Partners model. It Guides communities through the replication process outlined in the figure on page 1-3. Each community interested in model replication develops a plan for collaboration among agencies, organizations, and individuals in order to implement the model. Community resources and supports are needed to sustain the model and to create a lasting home for the program.

The replication process includes: *identifying communities* that will be able to replicate the Partners model, planning to use the model, implementing the model, and measuring success.

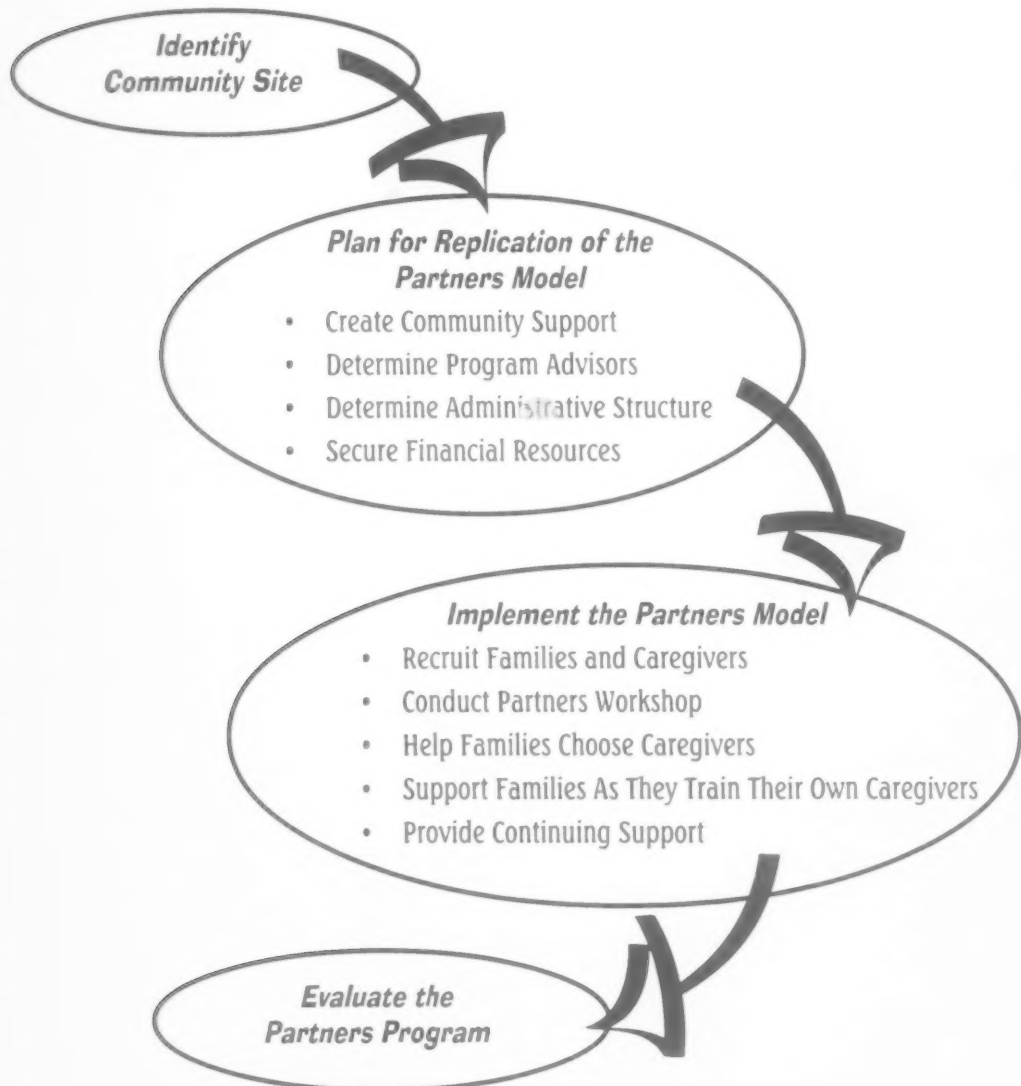
Your community will be a good candidate for replication if you have the following:

- support from agencies that provide, or are involved with, respite services,
- knowledge of current respite funding to support families without financial resources, and
- support and commitment from local early intervention programs, the school system, mental health or mental retardation programs, and/or family support programs



The Replication Process

Partners Community Implementation Process



The Replication Process

Each community needs to develop a *plan to use the Partners model*. Activities aimed at creating an awareness of family needs and the Partners model within a broad array of agencies, organizations, and individuals helps build a variety of community supports. The creation of an advisory committee brings expertise and resources that will ensure a quality program. Planning includes finding a home for the Partners program and knowing who is going to be responsible for implementing the program. Sometimes formal or informal interagency agreements will provide sufficient support, while in other communities new financial or personnel resources may be necessary for community replication.

This manual provides strategies and materials to help communities plan for and implement the **Partners family-centered respite care program**. CDR's Partners Plus has developed three additional manuals to be used in conjunction with this one. The **Trainer's Workshop Manual** enables community trainers to conduct the 6-hour Partners workshop for families and caregivers (the foundation of the Partners model of respite care). The **Trainer's Workshop Manual** includes the training content, sample agendas, overheads, and additional information that enables trainers to conduct an effective workshop for families and caregivers.

The **Family and Caregiver Manuals** are provided to each workshop participant, and are the basis of the workshop training content. Both manuals are designed specifically for families and caregivers to be used as resources during, after, and in absence of attending a Partners workshop. These manuals provide their readers with helpful



Planning a Partners Program

information about respite, caring for children with special needs, and building long-term respite relationships.

Communities that replicate the Partners model gather information from families and caregivers to *measure the success*, the quality and usefulness of training and support.

The Partners replication process will guide you in developing a family-centered respite program and in providing Partners training for families and caregivers. In planning for your Partners program, there are *four major tasks*: creating community support; determining program advisors; determining the administrative structure; and securing financial resources. A checklist is included in Section 2 to help your community plan your Partners program.

Planning Your Partners Program

- *Create Community Support*
- *Determine Program Advisors*
- *Determine Administrative Structure*
- *Secure Financial Resources*



Creating Community Support

Creating Community Support

The first task in planning for your Partners program is to create community support. A broad base of community support will ensure success for your Partners program. The design of your program will depend upon your community and its resources. A number of community agencies, organizations, and individuals may be involved in planning and implementing Partners.

Ideally, more than one agency will take part in planning and will contribute financial and other resources to the development of the program. Agencies and organizations may provide personnel, office space, and materials, workshop trainers, sponsor social events, or under write child care costs. Individuals may volunteer time, serving as advisors to the program or as trainers.

Because maintaining good community relationships is so important, it is an excellent idea to keep track of all communication. Provided in Section 2 is a sample form that may help your community maintain a *record of communication*.

The following pages offer some helpful hints in creating community support for your Partners program.

Consider the following questions when searching for community resources:

- Who in the community serves families of children with special needs?
- Which agencies or groups provide financial assistance for respite services?



Creating Community Support

- What parent organizations or support groups exist?
- Are there civic or religious groups that support special projects?
- Are there sororities or fraternities that support special projects?
- Who are the influential members of your community?

Ask some of the following groups/organizations to provide resources or supports:

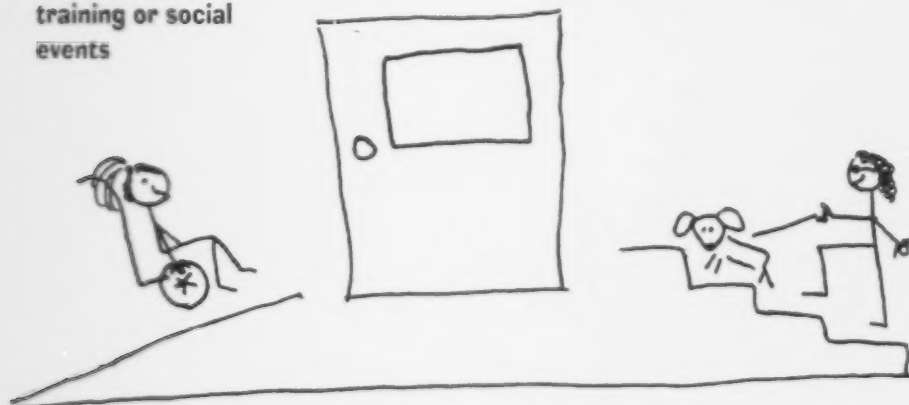
- Educational institutions or organizations
- Civic groups or religious organizations
- Parent organizations or support groups
- Disability advocacy groups
- Early intervention or public school programs
- State and local service agencies
- Hospitals and health organizations
- Local physicians or other health care professionals
- Local interagency coordinating councils
- Other interested groups or organizations.



Creating Community Support

Ask community partners to make any of the following contributions:

- Office space for personnel and materials
- Secretarial support
- Personnel/individuals to conduct training
- Space for training workshops and activities
- Funding to assist families in obtaining respite (e.g., stipends, vouchers)
- Stipends to caregivers for individual or group training
- Refreshments for group training
- Duplication of training materials
- Educational opportunities and resources
- Social opportunities for families and caregivers
- Promotional/awareness activities
- Transportation to training or social events



Naming Program Advisors

Determining Program Advisors

Community members and consumers of your services can participate as advisors to your respite program. The roles and responsibilities of your advisors can be to help plan your program, to market your services, to review materials, or to evaluate the program's success. Advisors can be individuals, focus groups, an independent committee, or a board of directors.

Advisors should have knowledge, experience, resources, and/or be influential community members. As advisors, the **expertise** of families and caregivers is essential. It will also be helpful to include individuals with skills in financial planning, community relations, or strategic planning. You may need representatives from local or state agencies, or individuals from the business community who have expertise in budgeting, finance, and funding. Your advisors can serve as a talent pool from which to draw future resources.

Focus groups can help you plan or review your program. Focus groups are frequently made up of consumers. A sample letter inviting parent participation in a focus group is included in Section 2.

Advisory committees may help to garner community support for your program and help to

Planning Your Partners Program

- *Create Community Support*
- *Determine Program Advisors*
- *Determine Administrative Structure*
- *Secure Financial Resources*



Naming Program Advisors

make decisions about how to plan and carry out your services. To ensure a family-centered program, families should comprise the majority of committee members. Other community stakeholders to be included may be from the fields of health, recreation, education, social services, early intervention, or from faith groups, civic groups, etc.

Advisory committees/groups are different from the **board of directors** for organizations. A board of directors is legally responsible for the agency or program, its management, and finances. A governing board sets policies. Advisory committees are not legally responsible for an agency, but can assist governing bodies in all aspects of management, except policy development. Advisory committees can provide objective program evaluation, develop strategies to overcome problems, and provide resources and expertise to support the program.

Included in Section 2 are **sample** roles and responsibilities of program advisors, an advisory committee agenda, and an advisory committee work plan.

Planning Your Partners Program

- *Create Community Support*
- *Determine Program Advisors*
- *Determine Administrative Structure*
- *Secure Financial Resources*



Creating Program Structure

Determining Administrative Structure

Whom will your program serve? How will your program be staffed? These are some critical questions about the administrative structure of your Partners program that will need to be answered in your planning.

Whom will the program serve?

Defining whom your program will serve may be critical in planning and establishing your Partners program. Defining your training audience will help in determining what community agencies and individuals will be involved and to what extent each will commit resources.

There are several characteristics of *consumers of respite* to consider, such as *age, disability, the family income, or place of residence*. For example, if you are going to serve children with mental retardation, look for support from agencies or organizations with special interest in supporting this population such as the Arc. If you are going to serve individuals with special health care needs, look to hospitals or health care agencies for support.

Caregiver characteristics such as knowledge, skills, and abilities may also influence decision making about the program. For example, if you choose to target trained child care providers, you may need to pay for their participation in group and/or personalized training.

Eligibility of respite consumers or caregiver characteristics may influence your ability to access state and local monies.



Creating Program Structure

grants, or donations. Funding sources may limit the number, or age, of clients served. Early planning about whom you will serve will ensure a clear focus in awareness materials and promotional activities. Clear eligibility parameters will help to attract appropriate consumers of your services and providers of respite care.

What services will the program provide?

Your Partners program will need to identify the types of services that will be available to support families and caregivers. Using the Partners model will mean that your program will at a minimum provide: Partners workshops for families and caregivers; support to families as they train their own caregivers; and **continuing** support to both families and caregivers.

Continuing support may consist of additional services, such as:

- phone consultations;
- home visits;
- meetings with families, caregivers, and/or community groups;
- a resource library;
- social activities;
- support groups and/or a parent cooperative for families and/or caregivers.

When deciding which support services your Partners program will provide, you will need to consider your financial and personnel resources, and supports currently available in your community. In Section 2, there is a discussion about providing continuing educational and social supports and services.



Creating Program Structure

How will your program be staffed?

Once you know the agency or group that will administer your Partners program, decide whether you need to hire a **program coordinator** or whether that role can be added to the responsibilities of existing personnel. Having one person to monitor and coordinate Partners activities will help ensure an efficient and effective respite program. Program advisors often have the expertise to serve as a resource to the coordinator, especially during the initial phase of program development.

The coordinator's first responsibilities may be to identify key agencies, groups, or influential people in your community to serve on the board of directors or, more typically, on the advisory committee. The coordinator may need to seek additional community support, write funding proposals, if the program will exist as a new or separate agency, or begin a public awareness campaign, in addition to seeking the help in developing the initial work-scope goals and in determining roles and responsibilities.

Coordinator roles and responsibilities may include developing awareness materials, coordinating group workshops and personalized training, purchasing materials, and collecting data for evaluation of services. The coordinator is often responsible for hiring and supervising Partners workshop training staff. He or she will supervise volunteer and/or paid personnel and ensure that they are educated in the method and content of training.

It is helpful to have at least two **trainers** to conduct Partners workshops. *A parent-professional team of trainers is highly*



Creating Program Structure

recommended. A family member's stories and perspectives can be extremely helpful for caregivers to hear. A parent or sibling, in the trainer's role, can contribute when family participants are reluctant to talk or can facilitate valuable discussion between families and caregivers.

Professionals from a variety of fields such as social work, education, health, counseling, etc., may be involved in Partners. It is helpful for your pool of professionals to have experience in training and knowledge of adult learning. Resources on adult learning are provided in Section 7. Additional information on learning styles and training tips can be found in the **Trainer's Workshop Manual**

Professionals and family members can also provide additional training to families and caregivers in related topics to enhance knowledge and skills. Topics that may supplement a Partners workshop include specific disabilities, adult learning, advocacy skills, or activities for young children. You may want to encourage family members and/or caregivers to be trained in First Aid and CPR. An additional list of topics that may compliment your basic Partners training is included in Section 2.

Securing

Planning Your Partners Program

- *Create Community Support*
- *Determine Program Advisors*
- *Determine Administrative Structure*
- *Secure Financial Resources*



Securing Financial Resources

Financial Resources

Although needs will vary based on your community and planned work scope, your Partners program will need personnel, facilities, materials, and other resources. Although some of these may be donated by agencies and organizations it is important to plan adequate funding to support your budget.

Funding for your Partners program may come from a variety of public and/or private sources. Public agencies such as local family support services or early intervention programs may supply charitable giving or funds for the provision of respite care. In addition to agency support, you may access corporate and other grants, personnel time, facilities, materials and even funds for respite care. Local groups such as interagency coordinating councils, civic and religious groups, and interested individuals may be possible contributors or volunteers for your program.

Besides personnel costs, facilities often require the greatest financial commitment. Your Partners program needs one place to call *home* -- a central place where families and caregivers can call or visit to obtain information or assistance. It is preferable to have one location for Partners staff to hold meetings and keep materials. You will want to consider several factors when choosing a home for your program including the mission, the reputation, and the logistics of the agency or organization, i.e., is this building location accessible to public transportation etc.?

Materials and resources needed may include flyers to announce Partners workshops, child care during workshops, and refreshments for participants. Caregivers and families



Securing Financial Resources

may need educational resources and stipends. Criminal or background checks on caregivers will help to ensure that children and families feel safe in developing new relationships with caregivers. If your community has the financial support necessary, a toll-free 800 phone number could also be a valuable resource to families and caregivers. Plan your budget in advance so you will have enough financial resources to cover your costs. A sample budget for your Partners program is provided in Section 2.

Consider the following sources of funding for your program:

- Grants from public agencies at the state and local levels
- Private foundation grants
- Donations from civic, religious, or other groups
- Donations from individuals, memorials
- Fund raising events
- Family support funds through state and community agencies
- State or local interagency coordinating councils
- Funds available from early intervention or other statewide services



Securing Financial Resources

Consider the following questions when selecting a home for the program:

- Does the agency or group provide respite or other services for children and families?
- Does the agency or group have a family-friendly image in the community?
- Is the facility easily accessible to families and caregivers?
- Are there supports or personnel available to answer inquiries and provide information?
- Can this agency or group serve as a central point of contact for the program?
- Is there a natural fit between the Partners program and the potential home?



Notes on this Section



2

Section 2

sample forms and
information for
planning your program

Sample Forms and Information

Sample Forms and Supplementary Information

- Developing Your Partners Program: Replication Checklist
- Project Inquiry Form
- Individual Contact Log
- Communication Log
- Letter of Invitation
- Advisory Committee Roles and Responsibilities
- Advisory Committee Organization Meeting Agenda
- Advisory Committee Workplan
- Supplementary Training Topics
- Budget



Developing Your Partners Program: Replication Checklist

Site: _____ Contact: _____

Activity	Person Responsible/Comments	Date Complete
Select local planning group (LPG) members		
Review Partners model		
Review Partners replication process		
Secure financial resources for: • the Partners program • a home • materials		
Identify program advisors (advisory committee/group)		
Define whom your program will serve		
Hire and/or select: • program staff • coordinator • trainers		



Partners Project Inquiry Form

Use this Sample Partners Project Inquiry Form to track families, caregivers, and others interested in participating in your Partners project.

Caller Information:

Date: _____ Message taken by: _____

Name: _____

_____ Family _____ Caregiver _____ Agency

Age of child: _____ Agency (if applicable): _____

Address: _____

City/County State _____ Zip: _____

Phone (Work): _____ Fax: _____

Reason for Inquiry / Call:

_____ Workshop information

_____ General respite information

_____ Respite funding

_____ Request for speaker/presenter

_____ Other (please specify): _____

How did you hear about Partners?

_____ From a family

_____ Newspaper article/press release

_____ From a caregiver

_____ Community agency

_____ Project staff

_____ Public awareness presentation

_____ Television

_____ Other (please specify): _____



Follow-Up:

- ☐ **Send Partners identity packet**
- ☐ **Send agency identity packet**
- ☐ **Send other materials**
- ☐ **Refer to other community resources**
- ☐ **Register for Partners workshops**
- ☐ **Add to mailing list**
- ☐ **Send copy to: _____**
- ☐ **File**

Comments:[illegible]

Individual Contact Log

Name: _____ Date: _____

Nature of Contact: _____

Follow-Up: _____



Use this Sample Partners Communication Log to track communication with families, caregivers, respite stakeholders, etc.

[illegible]

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Sample Introductory Letter to Families Informing Them of Partners

How to use this sample letter:

Prior to hosting your first Partners workshop, you may want to meet with families to inform them of your community's new Partners program. Meeting with families will give you a sense of their interest as well as times and locations for workshops that are best for them. Adapt this with your communities information, filling in the blanks, or altering as needed.

Dear:

_____ has a new program—Partners. Partners is designed to increase respite (temporary childcare) options for families of children with special needs. The program helps families identify and train their own respite caregivers and develop a system in the community to ensure continuation of respite services. Partners is a family-centered program that involves families in all phases of development.

Families will have the opportunity to be involved in many ways. One way is to participate in a focus group where you can share your ideas with members of the program staff. Since our first workshop for families and caregivers will begin soon, we are inviting you and several other families to participate in a focus group to share ideas on how we can best conduct and design trainings for families and caregivers.

We have selected the following date, time, and location for a meeting:

A member of the program will call you in a few days to see if you are interested in participating. Please feel free to call us as well to let us know if you will be able to attend.

The Partners staff are very excited about this new program and looks forward to meeting with each of you as we work together to expand respite options for families.

Sincerely,



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Sample Partners Advisory Committee: Roles and Responsibilities

Purpose:

To provide the Partners program with special guidance and counsel.

Member's Term: One Year

Composition:

The committee members consist of 51% family and caregiver representatives, and remaining 49% community representatives.

Meeting Attendance:

The Advisory Committee meets six times a year in alternating months.

Responsibilities:

- *Become informed about the program's goals and activities*
- *Promote Partners within your personal associations and to the community*
- *Assist in special problem-solving for the project*
- *Provide ideas and review program and materials development*
- *Assist in recruiting families and caregivers for respite*
- *Contribute knowledge and share experience*
- *Develop a plan for continued community support for continuing respite services*
- *Assist with project evaluation activities*



Sample Partners Advisory Committee Organizational Meeting Agenda

Date
Time

Agenda

I. Welcome and Introductions

II. About Partners

- *What is respite?*
- *Project goals*
- *Project activities*

III. About the Advisory Committee

- *Roles and responsibilities*
- *Workscope review*
- *Specific tasks and assignments*
- *Getting started*
- *Meeting schedule*



Partners Advisory Committee Workplan

Objectives	Activities	Initiation	Party Responsible	Status
1. To become informed about Partners goals and activities.	1.1 Attend Advisory Committee orientation meeting.	Date	Coordinator, Advisory Committee	
	1.2 Attend scheduled meetings on the 4th Monday of alternating months.	Date	Advisory Committee	
	1.3 Review Partners materials and advisory committee minutes in advance of meetings.	Date	Advisory Committee	
2. To work toward building a strong base of support and stakeholders within the community.	2.1 Promote Partners within personal contacts and community groups.	Date	Partners Staff, Advisory Committee	
	2.2 Recruit 4-6 additional members to represent families and community.	Date	Coordinator, Advisory Committee	
	a. Contact churches and pastoral care associations.	Date	Partners Staff	
	b. Invite participation by families who have received Partners training.	Date	Partners Staff	
	c. Contact civic groups that are focused on children's issues.	Date	Coordinator, Advisory Committee	
	2.3 Participate in Partners training workshops and presentations.	Date	Advisory Committee	



Partners Advisory Committee Workplan continued

Objectives	Activities	Initiation	Party Responsible	Status
3. To assist program staff in refining the model and revising training and public awareness materials.	3.1 Review and comment on Partners workshop flyers.	Date	Advisory Committee	
	3.2 Review and comment on Partners project brochure.	Date	Advisory Committee	
	3.3 Review and comment on Partners training manuals.	Date	Advisory Committee	
	3.4 Problem solve at meetings with staff to discuss model implementation issues.	Date	Advisory Committee	
4. To recruit interested families and caregivers to Partners training.	4.1 Generate listing of potential target groups.	Date	Advisory Committee	
	4.2 Identify contact persons.	Date	Advisory Committee	
	4.3 Assist project in making presentations.	Date	Advisory Committee	
5. To secure community resources for project continuation.	5.1 Support parent network for exchanging/bartering respite.	Date	Advisory Committee Partners Staff	
	5.2 Assist in developing respite co-op.	Date	Advisory/Partners Staff	
	5.3 Explore home for Partners program.		Advisory Committee Partners Staff	

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Examples of Supplementary Training Topics

- *First Aid*
- *CPR*
- *Disability specific workshops*
- *Communication/sign language*
- *Behavior management*
- *Positioning and handling techniques for caregivers caring for children with special needs*
- *Feeding issues for children with special needs*
- *Rehabilitation equipment (e.g. wheel chair, braces, etc.)*
- *Adapting toys for children with disabilities*
- *Talking to others about special needs*
- *Advocacy/Legislation awareness*
- *Activities to do with children*
- *Child development*
- *Relationships*
- *Principles of adult learning*
- *Training tips*



Sample Partners Budget

The following is based on four training workshops per year.
Additional budget considerations are listed on the back.

Expenses	Funds Available	Donated / In-Kind
Trainers' Salaries		
Parent (40 hours @\$15.50/hr)	\$100.00	\$520.00
Professional (40 hours @\$20/hr)		\$800.00
Coordinator (40 hours @\$15/hr)		\$600.00
Payment to Caregivers		
10 hours respite child care during personalized training (15 @\$5.15/hr)	\$772.50	
6 hours child care for families during workshop (6 caregivers @\$5.15/hr for 6 hours)	\$741.60	
Materials/Supplies		
Manuals purchased from CDR for 4 workshops (20 family and caregiver @\$15)	\$600.00	
Refreshments at workshops	\$75.00	
Postage, phone, utilities		\$400.00
"All Kids Like Cookies" props	\$50.00	
Training		
CPR/First Aid (10 caregivers)		\$300.00
Facility		
Home office space (@\$600/month)		\$7,200.00
Office supplies (@\$250/month)		\$3,000.00
Workshop training space (2 rooms @\$100 each)		\$800.00
Total	\$2,339.10	\$13,620.00



Other budget considerations:

Office equipment/furniture, advertisements, Xeroxing of training materials (agenda, ice-breakers), maintenance of the caregiver directory (personnel time, postage to mail to families), resource library, stipends for supplemental training for families and/or caregivers (optional), money to support actual respite (optional), facility use for social events, and any background/criminal history checks (optional).



3

Section 3

implementing your
Partners program

Recruiting Families and Caregivers

Recruiting Families and Caregivers

In order to recruit families and caregivers to participate in a workshop, your Partners program will need to use a variety of marketing strategies. You will want to have written awareness materials, news releases, and community announcements designed to reach specific community members.

In addition to helping with recruitment, marketing strategies will enhance community support for your program. Influential community members who could provide financial and personnel resources should be considered when developing promotional materials. Keep in mind who will be hearing, or reading about your program. Your approach and materials will vary depending on whether your *audience* is families, advisors, community agencies, or funding sources. Gear your marketing strategies to one or more specific target audiences.

Implementing the Partners Model

- *Recruit Families and Caregivers*
- *Conduct Partners Workshop*
- *Help Families Choose Caregivers*
- *Support Families as they Train their Own Caregivers*
- *Provide Continuing Support*

Since one of the best marketing strategies is *meeting and talking* with people, provide information about Partners and its training during regular meetings and telephone conversations with individuals in the community.



Recruiting Families and Caregivers

Public speaking informs a large number of people at one time and can immediately address their questions about the program. Present an overview of your program to community groups including religious, civic, advocacy and parent groups. Speak to agencies, colleges and universities, and health clinics. Invite community members to an orientation meeting to introduce your Partners program.



Direct mailing is a good way to reach people. Send brochures, flyers announcing workshops, and other promotional materials through the mail again targeting specific audiences such as families and referral sources. Include a telephone number to call and/or a registration form to mail back so that individuals can easily sign up for a workshop. If your budget allows, you may choose to use a graphic artist and professional printer or desktop publishing software for promotional materials.

Many agencies and groups produce **newsletters**. Your program may choose to produce a newsletter or submit announcements or articles to community newsletters. Some communities have parent newsletters or magazines that may publish feature articles.

Use the **media** to promote your program. Newspapers are likely to publish an interesting photograph with a caption. You may want to collect photographs and/or videos of events for future media coverage and awareness activities. Remember, when you take photographs and submit them to the media, you will need permission from the people in your pictures or videos. Sample release forms are included at the end of this section. A scrapbook for your program's history and events can be taken to future conferences and other public speaking engagements.



Recruiting Families and Caregivers

Families can recruit caregivers to participate in Partners workshops. Encourage families to tap into their informal supports (extended family members, friends, neighbors, and community programs) to train as their respite caregivers. People from within their own natural support network may be reliable and accessible over the long term. However, families with limited natural support may need your help to identify a caregiver. A directory of caregivers, and social events where families and caregivers meet, are ways in which the program can facilitate family and caregiver matches.

There are a number of strategies you can use to *encourage caregivers* to participate. Try using incentives, such as paying caregivers for their time to attend Partners workshops. An hourly rate, such as minimum wage, may attract child care professionals. Offering child care to caregivers as well as to families may also be an incentive for caregivers to attend Saturday or evening workshops.

Another powerful incentive is to pay caregivers for the time they spend with families in personalized training. In other jobs, employees are paid for their time spent in training. It should be no different for respite caregivers. Although the time spent in training varies some, families and caregivers spend up to ten hours learning together before respite begins. However, paying for training time may be a financial burden for some families. It is helpful if a community Partners program can pay caregivers for this time or help families gain access to available public funds to support training.



Recruiting Families and Caregivers

Strategies to promote awareness of your program:

- Brochures describing the program
- Flyers announcing training
- Paid advertisements on radio, TV, or in the newspaper
- Press releases for events
- Feature articles about families or caregivers
- Direct mailings to specific audiences
- A newsletter or newsletter articles
- Presentations at local agencies, meetings, or events

Strategies to recruit caregivers and families:

- Ask families to bring caregivers to training
- Place classified ads in local newspapers
- Distribute brochures and flyers to families through public schools
- Distribute brochures and flyers to agencies, organizations, and groups
- Post bulletins in public locations such as grocery stores, malls, churches, etc.
- Present at early childhood classes at colleges and universities



Conducting Partners Workshops

Conducting Partners Workshops

The purpose of the six-hour Partners workshop is to help families and caregivers understand the Partners model and family-centered respite. During the workshop, families develop skills in screening, interviewing, and training caregivers. Caregivers develop a basic understanding of caring for children with special needs. For families who do not bring their own caregiver to the workshop, this can be an opportunity for families to conduct an initial caregiver interview and begin their respite relationship.

Good planning will ensure that your six-hour workshop is a success. Planning for the workshop involves identifying and arranging space; compiling or obtaining Family and Caregiver Manuals; providing refreshments; and coordinating child care for participants. A sample checklist, included in Section 4, helps workshop trainers organize all the necessary information and materials for Partners workshops.

Implementing the Partners Model

- *Recruit Families and Caregivers*
- *Conduct Partners Workshop*
- *Help Families Choose Caregivers*
- *Support Families as they Train their Own Caregivers*
- *Provide Continuing Support*

The Partners Trainer's Workshop Manual (found in *Families and Caregivers as Partners: A Guide to Family-Centered Respite Care*) is an additional resource to help



Conducting Partners Workshops

trainers conduct the six-hour workshop. It contains helpful hints for how to conduct a Partners workshop, a script of what trainers can say, overheads, and examples of activities to break the ice and conclude the workshop. A flowchart to the **Trainer's Workshop Manual** is located on the following page.

In preparation for the six-hour workshop, consider the following:

- preparation,
- materials,
- training location,
- refreshments,
- child care,
- training tips, and
- evaluation measures.

Preparation

If your marketing strategies were effective, you should have a group of families and caregivers eager to attend a Partners workshop. As individuals express interest in your Partners program and/or in attending a Partners workshop, keep a record of their name, phone number, address and other pertinent demographic information. This will enable you to complete a mailing or in some way notify individuals about workshop dates and other Partners related information and/or activities.



Conducting Partners Workshops

Flow Chart to the Trainer's Workshop Manual

Introduction

The first section of the Trainer's Workshop, Family, and Caregiver Manuals have the same Introduction.

How To Use the Trainer's Workshop Manual

The second section of the Trainer's Workshop Manual tells the trainer how to use the manual.

Welcome to the Partners Workshop

Workshop information for all participants begins in the Trainer's Workshop Manual at this section.

Sections 1-4: Participants Work Together

All workshop participants work together during sections 1, 2, 3, and 4, where the information is the same for both families and caregivers:

Section 1: About Respite

Section 2: Building Partnerships: Communication

Section 3: Building Partnerships: Families and Caregivers Working Together

Section 4: All Kids Like Cookies Activity



Conducting Partners Workshops

Sections 5-10: Participants Work Separately

After completing section 4, the group splits into families and caregivers, each working with a trainer on topics that are different:

Family Break-Out Session

- Section 5-F: Finding Respite Caregivers*
- Section 6-F: Interviewing Caregivers*
- Section 7-F: Developing a Personalized Training Plan*
- Section 8-F: Resources*
- Section 9-F: Forms for Sharing Information*

Caregiver Break-Out Session

- Section 5-C: Disabilities Awareness*
- Section 6-C: Understanding Child Development*
- Section 7-C: Children with Special Needs*
- Section 8-C: Becoming a Caregiver*
- Section 9-C: Resources*
- Section 10-C: Forms for Sharing Information*

Final Activity: Participants Work Together

After completing their sections, the two groups return for the Final Activity, involving daily routines to help develop a personalized training plan.



Conducting Partners Workshops

Maintaining a *registration list* for the workshop can help you plan for the event. You will be able to limit the number of no-shows if you use some simple strategies, such as calling or sending a post card as a reminder to those who register. A small fee can be used to ensure registrants actually attend. However, many programs choose not to charge families to enroll in workshops. An alternative strategy to ensure good attendance is the use of a refundable registration fee.

To *prepare participants* for the workshop you may want to remind them about workshop content, times, locations, and about items they should bring for children who will be in child care during the workshop. Families who bring children should plan to come at least twenty minutes early to meet with their caregivers and become familiar with a new environment. A sample workshop *agenda* included in Section 4 can be distributed prior to your Partners workshops.

Materials

CDR has developed **Family and Caregiver Manuals** that participants will be able to use during and after the workshop as a resource. Families will depend on their manuals to help them develop personalized training plans for their caregivers. Manuals for each workshop participant may be purchased from CDR, or one master set can be purchased and duplicated by your Partners



Conducting Partners Workshops

program for each participant. You may wish to compare the costs in personnel and resources to determine which method of obtaining manual materials is best for your program.

You'll need ***Additional supplies*** such as name tags, pencils, pens, and stickers. Name tags help trainers learn participants' names and facilitate discussion between families and caregivers. Using different colors for caregiver and family name tags will help families identify caregivers and help trainers separate participants into small groups for activities during the workshop. It is helpful to supply participants with pens or pencils and high lighters to use during the workshop. You may want to purchase pens or pencils with your logo, phone number, and address on them as a promotional tool for your Partners program. Pencils or other promotional items can be used as incentives for workshop participants who volunteer to participate in activities. You can give high lighters to all participants or just place a few at each table to be shared. Participants also like getting colorful tags or sticky dots to use as markers in sections of the manual, and extra paper or sticky pads to jot down ideas, comments, and/or questions.

Bringing books, videos, and other resources or an annotated bibliography to the workshop shows participants what materials they can borrow or purchase. If you plan to make resources available on loan, be sure to establish a catalog system that allows you to track them so materials will be returned.



Conducting Partners Workshops

Workshop Location

Think about the *location* where your workshops will be held. If your program serves a large geographic area, you may want to use several locations to make it easier for participants to attend workshops. Make sure the buildings you conduct your workshops in are centrally located and physically accessible for participants with disabilities.

There may be workshop space available in your building or other nearby locations, at no cost to you. However, if space is not readily available, you may want to explore the use of local churches, synagogues, schools, or other facilities. Often, space can be found in the community free of charge or for a small donation.

It is necessary to have access to at least two rooms for adult use and a place for child care if you are offering that service. One of these rooms should be large enough to accommodate the entire group. The other, for use in small *group activities*. Churches or synagogues work well if you provide child care because many have nurseries and/or a *kitchen* for preparing refreshments. Early intervention programs, schools, child care centers, or recreation centers often have rooms and materials appropriate for *child care*.

The space you use should be comfortable (e.g., air conditioned/heated) and have access to telephones and rest rooms. When *arranging the space* for the workshop, consider size of the group and arrange the tables and chairs so that participants can easily see the trainers and



Conducting Partners Workshops

also talk freely with others. For a group of approximately 20 participants, tables can be arranged in a U-shape. For larger groups, circular tables can be used. Groups larger than 30 are not recommended for Partners workshops. Due to the nature of small group activities in the workshop and break-out sessions designed to foster participant sharing, smaller groups (under 30) are more conducive to meeting Partners workshop objectives.

If your Partners program plans on holding workshops in a variety of locations to help reach as many people as possible it is helpful to have suitcases with wheels for transporting resources, manuals, and other materials easily. When you travel, it is important to plan ahead and make sure you have packed all the materials and items you will need.

If you use borrowed space, you may not know what resources are available within the building, or how much time and effort it will take to arrange the rooms to meet your needs. For this reason, it is helpful to be able to *set up* the day before the workshop. If that is not possible, plan to arrive at the location in time to arrange the room and set up the workshop, activities, resources, and refreshments.

Be sure to give participants clear directions to workshop locations. A copy of a map or specific written directions are helpful in ensuring that participants can find their way.



Conducting Partners Workshops

Refreshments

Depending on the time or length of your workshop, you may decide to offer snacks and/or lunch for participants. To reduce costs, your program may ask participants to bring their own lunch. Other options are to have participants leave for lunch and then return, or to schedule workshops over two evenings or two mornings to avoid a meal altogether.

Having families, caregivers, and their children *eat a meal together* has proven to be successful in helping families and caregivers match. Not only do participants have an opportunity to meet each other, but families and potential caregivers have an opportunity to watch caregivers interact with children. For some potential caregivers, this may be the first time they meet children with special needs and talk with their families.

Child Care

Without child care, many families will be unable to participate in your Partners workshop. One way to help families attend is to provide quality child care. Child care is also an opportunity for recently trained caregivers to obtain hands-on *experience caring for children* with special needs. The group care experience gives families an *opportunity to meet* and observe potential caregivers, thus facilitating family and caregiver matches. By providing child care at workshop sites, you are providing caregivers with a chance to practice their skills with the support of having families and other caregivers present. When



Conducting Partners Workshops

arranging child care it is helpful to select at least one seasoned caregiver to serve as a mentor for new and/or inexperienced caregivers in group care.

Workshop participants should **preregister** their children so you will know how many children will be attending and how many caregivers you will need to provide care. You will need to have one or two extra caregivers available for unexpected arrivals. Or be prepared to tell participants who have not preregistered that you cannot provide care for more children than anticipated.

In order to ensure successful group care experiences for children, families, and caregivers, you must use appropriate child care settings. Make sure the rooms will accommodate the number of children's activities appropriate for their ages, and any **special accommodations** that may be needed. For example, children with wheelchairs will need space to maneuver.

Families should be encouraged to come early to help familiarize their children with the setting and to share necessary information about caring for their children. It is beneficial to both families and caregivers to be **nearby** during the workshops, if help or guidance is needed. This is especially true for caregivers who are newly trained to care for children with special needs.

You may be able to find caregivers who are willing to **volunteer** their time in order to gain a valuable and satisfying experience. If not, you will need to pay caregivers through your program funds or seek support from other sources.



Conducting Partners Workshops

Workshop Tips

Good training combines lecture, audiovisuals, and individual and group activities. In the **Trainer's Workshop Manual**, there are hints for conducting the workshop and information about adult learning. Reviewing this material will help ensure that your workshop is appropriate to varied adult learning styles and preferences.

During the workshop, real-life illustrations convey content in meaningful ways. The **Trainer's Workshop Manual** provides *stories from real families*. Trainers who have family members with disabilities can tell their own stories.

Here are some tips on making training more meaningful and enjoyable:

- Have knowledgeable trainers who are well prepared
- Develop and follow an agenda
- Foster a respectful, open, and informal atmosphere
- Use a little humor and cartoons to illustrate points
- Encourage discussion and an open environment for interaction
- Include fun activities and energizers

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Conducting Partners Workshops

Measuring Your Success

In order to ensure the quality of the workshop, Partners workshop *trainers need feedback* from participants about their presentation styles and their use of the Partners materials. Participants may rate or comment about the organization of the workshop, the helpfulness of presenters, the usefulness of materials, or what they learned during the workshop. A sample workshop training evaluation is included in Section 6.

It is useful to let workshop participants know how important and valued their comments are and to thank them in advance for taking the time to provide you with feedback. Participant comments will inform you about needed changes in your presentation.

In addition to evaluation of the six-hour workshop, it is extremely useful for *Partners programs to receive feedback* regarding the success of your respite program. You may wish to collect *pre and post knowledge and comfort measures* to determine what caregivers have gained from participating in the workshop. Program evaluation data may be used to educate potential funding sources, advisory committee members, the media, or other people whom you would like to receive more information about the program. Program or model evaluation measures are discussed and sample instruments are provided in Section 6.



Choosing Caregivers

Helping Families Choose Caregivers

After the workshop, families who did not bring their own caregivers to training match up with trained Partners caregivers to begin *personalized training*. During the workshop, families think about what they will want from a caregiver and learn how to screen potential caregivers. Now, families interview caregivers to find out if their caregiving preferences and styles are similar.

Families may meet caregivers in the workshop and may begin interviewing in preparation for personalized training. Other families may try some additional strategies to recruit caregivers or decide to postpone personalized training until a later date.

Families who were unable to either bring their own family or friends to the workshop as caregivers or meet a caregiver at the workshop may want help facilitating matches. The **Family Manual** contains a list of community resources available to families to help them get in touch with potential respite caregivers. You may be aware of additional resources in your community that families can contact to help them find caregivers.

Implementing the Partners Model

- *Recruit Families and Caregivers*
- *Conduct Partners Workshop*
- *Help Families Choose Caregivers*
- *Support Families as they Train their Own Caregivers*
- *Provide Continuing Support*



Choosing Caregivers

A Directory of Potential Caregivers

Your Partners program may want to supply families with a directory of trained caregivers. Your *directory of potential caregivers* should be regularly updated so that families can find potential caregivers to interview and train.

Computer Databases are easy to maintain and are extremely helpful for a variety of reasons. A database can store your list of potential caregivers and help you track workshop participants. You will be able to retrieve caregiver or family names based on their caregiving preferences or geographic locations. Databases can store large quantities of information, can sort the information in many ways, and can create reports and mailing labels. There are many database programs available, from simple and "user friendly" to elaborate and complex. Whether you choose to keep this information as hard copies in individual files or on a computerized database, we highly recommend gathering and storing this information.

Once you spread the word about Partners, people will be calling for additional information. It is important to record names, addresses, phone numbers, interests, etc. for your database. You may also want to record what type of help you gave the caller (i.e., questions answered, added to the mailing list, registered for a workshop, referred to another resource, etc.).

Your database will help you organize the information you collect from callers into a system that will allow you to identify families and potential caregivers who have called for information so you can notify them of upcoming



Choosing Caregivers

workshops. You may want to use your database to identify agencies who can distribute information about Partners to their customers or clients.

Some of the other information you might want to keep on file includes:

- Date training was completed
- Age of child(ren) in the family
- Disability of the child(ren)
- Caregiver certifications
- Agency affiliations
- Status (i.e., if they are a caregiver, family, or with an agency)

Background Checks

If your Partners program plans to provide a caregiver directory for families, you will want to make some decisions about screening and background checks.

Screening of caregivers may include criminal/sex offender background checks, reference checks, department of motor vehicles background checks, and/or child abuse registry checks.



Choosing Caregivers

Background check forms can usually be obtained from your local police department and the department of human or social services, typically for a small fee.

Your Partners program may routinely do criminal or other official background checks on all caregivers who participate in the workshop or who are registered with your program. You may prefer to do checks on caregivers only when requested by a family, or to provide families with information on how to do their own background checks.

Partners encourages all families to complete reference checks calling at least two former employers or other people who know the caregiver, excluding relatives. The family or staff from your program, should ask reference questions such as: *How long have you known the person? How would you describe them? What are their strong points in working with children with special needs?* A sample reference check form is included in the **Family Manual** component of **Families and Caregivers as Partners: A Guide to Family-Centered Respite Care**.

Decisions your program will need to make about screening caregivers:

- Will there be selection criteria for Partners caregivers?
- Will your program require any background information checks or reference checks?
Who will pay for them?



Choosing Caregivers

- How much help will your program give families in checking criminal records or doing reference checks for caregivers?
- Will the program perform checks on caregivers who have been recruited by families or just on caregivers who have been recruited by the program?
- Will the program endorse caregivers or simply provide a directory of caregivers' names and phone numbers specifying that although they have attended training, families are responsible for ensuring a good match and/or performing background checks?

Matching Opportunities

Educational or social events can help facilitate family and caregiver matches. Your program can host a variety of training events with topics such as first aid, stress and coping, or handling difficult behavior. Social events such as picnics, holiday parties, or children's festivals are more informal events that not only help families choose caregivers, but also help families meet each other. Family support groups promote networking among families.

Families who are uncomfortable calling strangers on a list may be interested in participating in Partners social events that promote family/caregiver matches. *Parents' Day Out* is a respite opportunity for parents that, besides offering respite, brings potential caregivers, families, and their children together to get to know each other better.

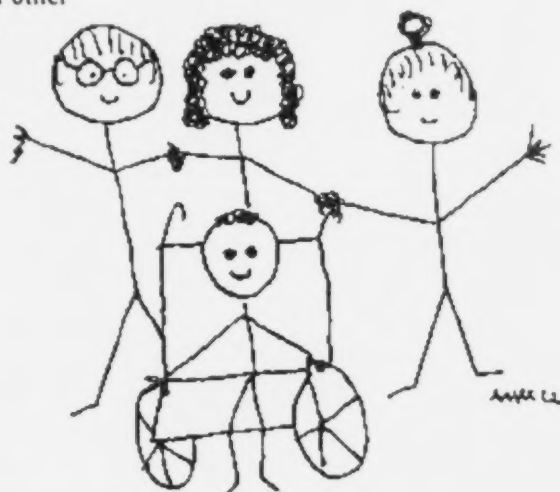


Choosing Caregivers

Parents' Day Out can also be a learning experience for caregivers. Newly trained caregivers can watch and learn more about caring for children with special needs from experienced caregivers. Caregivers tell us that having the support of other caregivers in group care helps them to feel more confident in their own abilities to care for children with special needs. The group caregiving experience can also lead to increased frequency of caregivers responding to the respite needs of families who call them.

Group care works well when at least one experienced caregiver acts as a mentor or lead caregiver for the rest of the group. Mentor caregivers can help less experienced caregivers by showing them what to do and encouraging them to practice new skills.

Another option for matching caregivers is to choose to form **a family cooperative**. In a coop, families can provide respite for each other without exchanging money. Family support groups in which families get to know each other well are likely to foster coop arrangements.



Choosing Caregivers

Essential elements for hosting a "Parents' Day Out":

- Schedule date, time, and length of event
- Decide who should attend and if a fee will be required
- Inform families of the event and register families as they confirm
- Determine the amount of children attending
- Obtain adequate caregiver coverage, preferably of both new and experienced caregivers
- Find adequate, appropriate space for child care
- Have plenty of toys and supplies appropriate for each child's age and development available
- Encourage families to meet with caregivers before and after to share information and to get to know caregivers
- Ensure that families have an opportunity to observe caregiver and child interactions
- Schedule time for families, caregivers and/or Partners staff to debrief together afterwards



Supporting Caregiver Training

Supporting Families as They Train Their Own Caregivers

Families will vary in the extent to which they rely on your Partners program to help them through this next phase of training. Your program can provide guidance, technical assistance, and emotional support to both families and caregivers.

During the six-hour Partners workshop, families receive opportunities to learn and practice new skills. In addition, their manual will be a resource in personalized training of caregivers. The **Family Manual** contains a step-by-step process for personalized training and various forms that guide the family through the experience. Caregivers will also rely on their **Caregiver Manual** as a resource after group training. It will be helpful to your program's staff and trainers to be familiar with the

Family and Caregiver Manuals in order to support families and caregivers as they begin personalized training.

Implementing the Partners Model

- *Recruit Families and Caregivers*
- *Conduct Partners Workshop*
- *Help Families Choose Caregivers*
- *Support Families as they Train their Own Caregivers*
- *Provide Continuing Support*



Supporting Caregiver Training

Successful partnerships between families and caregivers result when both work toward building a relationship. As in any relationship, good communication between families and caregivers is important in building successful respite relationships.

Families need to spend enough time in preparing caregivers, so they feel comfortable in caregiving. Caregivers need to know that the family is willing to give them the support they need to be successful in their partnership.

A caregiver must have a genuine desire to help a family meet their respite needs and a willingness to learn from families. Caregivers who listen, and learn a family's way of caring for their child, help that family feel comfortable in leaving their child. Caregivers who ask appropriate questions and follow through on instructions earn families' confidence.

A good respite relationship is one of mutual respect. Respect is shown in appreciating others' knowledge and experience, and being considerate of others' time and energy. Using a little humor can help caregivers relax while learning the skills necessary to care for a family's child. Allowing for flexibility in caring for a child is a way for families to show they value a caregiver's experience.

Families must also show appreciation to their caregivers. A good first step is letting caregivers know how much having respite means to them. Remembering that caregivers have a need to spend time with their own families and friends shows respect for a caregiver's personal life and will help families to keep their caregivers.



Supporting Caregiver Training

Providing Continuing Support

Your Partners program can support families and caregivers in a variety of ways. Often families and caregivers need only minimal support beyond the Partners workshop. Support can come as recognition for a job well done or as help in making a phone call.

Strategies for support can include telephone consultation, home visits, or even a postcard with a few words of encouragement. On occasion, you can support families by making a referral or creating linkages between the community. Referrals to other services or financial resources may help ensure respite. To achieve a successful and lasting program, consider what resources your community has available to ensure adequate support for families and caregivers.

It is critical to recognize your program's role in fostering successful respite relationships and ensuring long term partnerships. Flexibility in how your program supports families and caregivers is essential. Listen to families and caregivers and respond to their individual needs. Using families and caregivers as advisors will help make decisions about the kinds of support your program should offer.

Your program's support may be educational, using strategies such as:

- offering resource materials (i.e. a lending library), or
- providing additional training.



Providing Continuing Support

Your program's support may be social using strategies such as:

- holding special events, or
- having family support group meeting.

Your program's support may combine many strategies.

Materials Loan

Access to a **resource library** and the Internet is very beneficial for families and caregivers. Up-to-date technical information on disabilities and special health care needs is frequently requested. Families often request strategies for handling difficult behavior and coping with stress. Local libraries, public schools and early intervention programs may be able to provide both reading and loan materials and Internet access. If resources are not accessible through community agencies or programs, you will

Implementing the Partners Model

- *Recruit Families and Caregivers*
- *Conduct Partners Workshop*
- *Help Families Choose Caregivers*
- *Support Families as they Train their Own Caregivers*
- *Provide Continuing Support*



Supplemental Training

want to collect written materials for loan and keep them readily available for workshop trainers to take with them to display at workshops.

Supplemental Training

Educational opportunities related to caring for children with special needs can increase families' and caregivers' knowledge and skills and many families and caregivers find it helpful to attend training *beyond* the Partners initial six-hour workshop. While skill-building workshops are valuable to families and caregivers, costs may be prohibitive. Your Partners program may choose to provide funds for these activities, as a way of offering additional support to families and caregivers.

Caregivers are often interested in additional training related to the special needs of children with disabilities. When caregivers learn more about caring for children with special needs, they become even more comfortable in caregiving. Additional training may also involve certifying family members or caregivers in First Aid and CPR to increase their awareness of safety and lifesaving techniques.

Additional training *benefits* the program by facilitating possible matches between families and caregivers. Families and caregivers have found that additional training offers them more contact with each other, making it easier to get to know and to find ways to support each other during respite care.

Your program will need to decide whether and how much of its budget can *support supplemental training*. A Partners program can offer scholarships to families and caregivers for workshops



Social Support Strategies

and seminars. You may want to budget money for postage and phone calls to notify families and caregivers of upcoming workshops.

Social Support Strategies

Families of children with disabilities or special health care needs share common interests and concerns, and often seek social support from one another. Families tell us how helpful it is to hear from another family who has a child with a similar disability or life experience. Your Partners program can help families to meet each other.

A *Family Directory* can help promote parent-to-parent support. A *Caregiver Directory* can promote both matches between families and caregivers and caregiver-to-caregiver support. These directories can be kept by the program or distributed to families or caregivers who want them. An individual who wants to be included in the directory should give permission to share his or her name, address, phone number, and perhaps a brief description of their family or caregiving experience. Sample release forms are included in Section 4.

Social events that include caregivers help facilitate matches with families and can build social supports for both families and caregivers. Families and caregivers can develop friendships in social contexts such as parent and child groups, pot luck dinners, and recreational events. Your Partner's advisory committee may designate a social committee that could obtain support from the community for social activities. For example, the committee could ask



Family Support Groups

for donations or reduced-price tickets to a family event or theme park.

Many caregivers are interested in receiving support from other caregivers with similar interests and concerns for providing respite care. Regularly scheduled, monthly *meetings for caregivers* can offer additional training and learning through shared experiences. To defray costs, caregivers can take turns hosting meetings and take turns providing refreshments. Caregivers have said that having this kind of regular, continuing support helps them remain interested in providing respite to families.

Family Support Groups

Support groups help families unite to deal with a range of issues unique to families who have children with special needs. It is very helpful for families to have an updated listing of local support groups and available resources in the community. If local support groups do not exist, or are inadequate to meet your families' needs, then your Partners program can help families form a group.

Families who are likely to participate in a support group may be those who want:

- Social opportunities for themselves and their children
- Information about specific disabilities

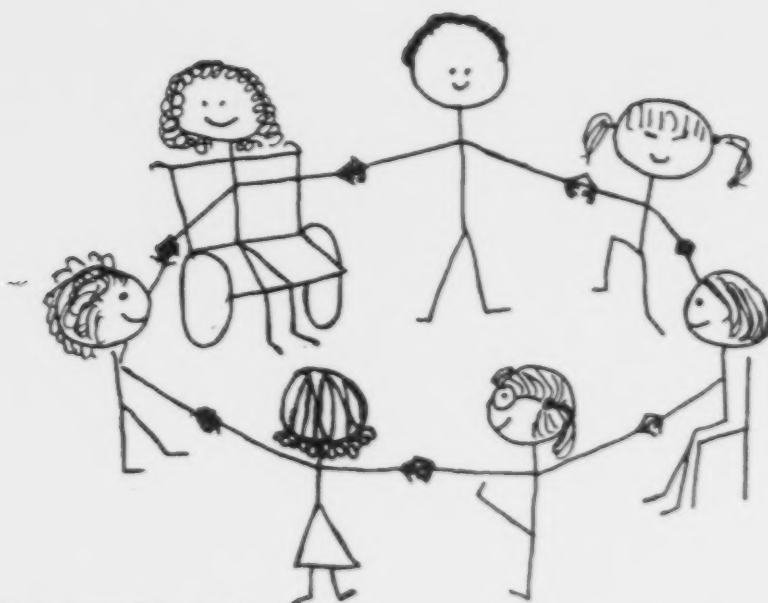


Family Support Groups

- Information about how to plan for the years ahead
- Information about educational, health care or other community services
- Information about independent living and work opportunities for their children
- To know how to get *respite*

It has been great for me to come to training today and hear what it is like for other families. I don't know other families to talk to.

- Debbie Warren, 1996, Parent



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Section 4

sample forms
and information
for implementing
your program

Sample Forms and Information

Sample Forms and Supplementary Information

- Sample brochure
- Sample article
- Sample press release
- Sample flyer
- Implementing Partners Planning for Workshop Checklist
- Workshop Agendas
- Permission for Videotape with Sound/Photograph Use
- Presentation/Workshop Checklist
- Permission to Release Caregiver Name
- Permission to Include Information in Family Directory



Sample Brochure

You may want to develop a brochure to help people learn about your Partners program. You can easily develop a brochure by using desktop publishing software or by using the expertise of a graphic advisor and printer. Your budget will guide your choice to use one or the other.

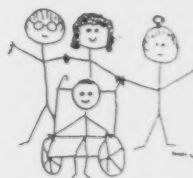
Child Development Resources
1490 Government Road
Williamsburg, VA 23185

For more information, contact
Partners Plus.

Child Development Resources
1490 Government Road
Williamsburg, VA 23185
Phone: (757) 220-1168
Fax: (757) 253-1779
e-mail: cdtraining@ie2.net



CHILD DEVELOPMENT RESOURCES



PARTNERS PLUS OUTREACH Families and Caregivers in Partnerships

Caring for Children
with Special Needs

"Think of a candle that slowly
burns. The flame flickers and
goes out just as a candle we
need to be re-lit 100."

A Parent

Support for the project is provided under grant
number H324R980006 from the U.S. Depart-
ment of Education, Office of Special Education
Programs. Plans of view or opinions do not,
however, necessarily represent official views
or opinions of the Department of Education.



CHILD DEVELOPMENT RESOURCES

THE PARTNERS PLUS OUTREACH PROJECT...

- works with communities to establish a Partners Plus respite program through replication of a proven model
- helps families learn how to find and train respite caregivers
- supports individuals in becoming caregivers

WHAT IS RESPITE?

Respite is temporary child care that relieves families from the daily responsibilities of caring for their children with special needs. Together families and caregivers decide when, where, and under what terms respite will take place.

WHO CAN PARTICIPATE?

- Communities interested in creating a Partners Plus respite program
- Families of children with special needs who might need or want respite
- Individuals interested in learning about providing care for children with special needs

PARTNERS PLUS OUTREACH OFFERS...

- Support and training to communities, families, and caregivers
- Resource manuals for communities, families, and caregivers
- A proven model for family-centered respite

The project helps communities develop a respite program using a train-the-trainer approach.

The project helps families recruit caregivers and plan training specific to their children's needs. In training, families and caregivers:

- meet one another
- learn about caring for children with special needs
- discover the challenges children with special needs experience
- build successful partnerships with each other



CHILD DEVELOPMENT RESOURCES...

a private nonprofit agency has won national recognition for its services for young children and their families and technical assistance to the professionals who serve them. Partners Plus, initially serving Virginia and now offering its respite model to other states, is one of several programs offered by Child Development Resources.



FOR MORE INFORMATION

please call Partners Plus staff or
complete and return this form.
Phone: (757) 220-1168 Fax: (757)
253-1779 e-mail: cdtraining@ie2.net

Name: _____
Address: _____
Phone: _____



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Sample Newspaper Articles

CDR offers parents help with respite care

by Lisa L. Ownby

Where do parents turn when they need a break from the everyday demands of caring for their children? Most families can find a friend or neighborhood babysitter to get a night out but for families of children with disabilities and/or special health care needs it's not that easy. Finding a caregiver who is available, comfortable, and knowledgeable about caring for a child with special needs can be difficult.

These parents also need a break and can

benefit from respite (temporary child care). Respite is described by one family in this way: "think of a candle that slowly burns, the flame flickers and goes out and just as a candle, we need to be re-lit, too."

PARTners Plus, a program of Child Development Resources (CDR) is designed to assist families of children (birth-8) with special needs in selecting and training their own respite caregivers. PARTners also offers training and support to individuals interested in serving as caregivers for families.

PARTners holds workshops regularly for both families and potential caregivers. At the workshops participants will learn about caring for children with special needs; meet other families and caregivers; discover some of the challenges children with special needs experience, and talk about how families and caregivers can build successful partnerships.

These workshops are free of charge and all participants receive a resource notebook. Staff are available after the workshop to help families train the caregiver they select. PARTners will pay caregivers up to 10 hours of time spent in training. For more information ask for PARTners Plus staff at (757) 566-3300.

After completing a PARTners workshop a parent said, "it's sometimes difficult to make the time to find a caregiver when you have a child with special needs... but having the support of CDR gives us peace of mind to enjoy time away. For our family, respite is a life saver!"

Lisa L. Ownby, M.S.W., is the project coordinator for PARTners Plus



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Sample Press Release and Feature Articles

How to use:

Adapt this to include your community's information and submit to local media.

FOR IMMEDIATE RELEASE

CONTACT:

Name

Phone Number

Caring for Children with Special Needs

(City/Town) Date -- _____'s Partners program is conducting a workshop on caring for children with special needs. Families of children with special needs will learn about respite (short-term care for their children) and how to find and train caregivers. Individuals interested in becoming caregivers will learn about working with children with special needs and their families.

The workshop will be held on _____ from _____ to _____ at _____.

Accommodations for participants with special needs, including sign language interpreters, will be made available upon request. Child care will be available for those who pre-register. For more information, or to register, please call _____.

###



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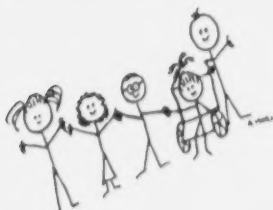
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Sample Flyer

The following is a sample Partners Plus flyer.

Partners Plus Free Workshop



Caring for children with special needs -

Finding a babysitter is usually a routine chore for most families with young children. But parents of children with special needs often have a hard time finding caregivers who are knowledgeable, comfortable, and available to care for their child with special needs.

Partners Plus helps families learn how to find and train caregivers to provide respite (temporary child care). This project also offers support and training to individuals interested in helping families by serving as a caregiver for their children.

Special Accommodations

can be made with sufficient time of request. Participants will receive a free notebook and child care is available for those who pre-register. Light refreshments will be provided; however, participants will need to bring a bag lunch.

When?

Saturday, November 20,
1999
9:00 a.m. until 1:00 p.m.

Where?

Child Development Resources
150 Point Of Woods Road
Norge, Virginia
757-566-3100

How do I sign up?

Call 220-1168 to register and
receive more information.

AT THE WORKSHOP FAMILIES AND CAREGIVERS WILL

- learn about caring for children with special needs
- meet other families and caregivers
- discover some of the challenges children with special needs experience
- talk about how families and caregivers can build successful partnerships

It's free!

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Implementing Partners: Planning for Workshop

Site: _____ Contact: _____

Activity	Person Responsible/Comments	Date Complete
Promote community awareness		
Recruit families and caregivers		
Schedule Partners group training • trainers • date • location • time		
Develop training announcement and distribute		
Register training participants and create/maintain database		
Plan for child care during training • Register children • Recruit caregivers		



Planning for Workshop continued

Activity Person Responsible/Comments Date Complete

Prepare training materials for participants • manuals • agenda • ice breaker • evaluation forms		
Call registered participants to remind them to attend training		
Purchase or provide refreshments		
Prepare/set up rooms at training location		
Evaluate training		
Provide follow-up technical assistance such as: • Help families choose caregivers • Support families as they train their own caregivers • Provide continuing support		



Partners Workshop Agenda

Date

Location

Time

Part I

Time Registration and Light Refreshments

Welcome and Introductions

About Partners

Communication

Time Break - 5 minutes

*Building Partnerships: Families and
Caregivers Working Together*

Preview of Coming Attractions

Time See Ya for Part 2!



Partners Workshop Agenda

Date

Location

Time

Part II

Time Registration and Light Refreshments

Time Activity: All Kids Like Cookies

Time Break Out Session for Families
Finding Respite Caregivers
Interviewing Caregivers
Developing an Personalized Training Plan

Time Break Out Session for Caregivers
Understanding Child Development
Disabilities Awareness
Children with Special Needs
Becoming a Respite Caregiver

Time Break - 5 minutes
Practice Activity: Using Daily Routines
Wrap up and Evaluations

Time Congratulations! You are on your way!



Checklist of Materials and Equipment for Partners Workshop

Date: _____ Time: _____ Location: _____

Purpose: _____

Number Expected to Attend: _____ Presenter(s): _____

Room and Facility Preparation

- _____ Table for Registration
- _____ Table for Display Materials
- _____ Table Space for All Participants
- _____ Tables Arranged in a Horseshoe Shape
- _____ Chairs for All Participants
- _____ Extra Tables for "All Kids Like Cookies" Activity
- _____ Tables for Lunch or Refreshments (optional)
- _____ Overall Agenda for Training
- _____ Rooms for Childcare According to Numbers of Children Attending
- _____ Childcare Rooms with Accessibility to Lavatories (Preferably in Room)

Childcare Preparation

- _____ Caregiver Sign-In Sheet
- _____ Appropriate Toys and Activities
- _____ Activity Supplies
- _____ Snacks
- _____ First Aid Kit
- _____ "Partners Plus Workshop Childcare Information"

Getting Started

- _____ Refreshment Supplies (optional)
- _____ Name Tags or Tents
- _____ Sign-In Sheets
- _____ Initial Family Survey

Getting Started, continued

- _____ Comfort Measure-Pre
- _____ Knowledge Measure-Pre
- _____ Participant's Manuals
- _____ Overall Agenda for the Training
- _____ Getting Acquainted Activity
- _____ Pencils for Participants
- _____ Sample Press Release and Feature Articles form (optional)
- _____ Permission for Videotape with Sound / Photo Use (Enough for All Participants)

Section 1

- _____ Handouts
- _____ Prepared Overhead Transparencies / Flip Charts
- _____ Overhead Projector and Screen (optional)
- _____ Markers for Either Flip Charts or Overhead Transparencies
- _____ Flip Chart Stand
- _____ Incentives for Participation in Methods of Communication Activity

Section 2

- _____ Prepared Overhead Transparencies / Flip Charts
- _____ Overhead Projector and Screen (optional)



Workshop Materials, continued

Section 2, continued

- ___ Markers for Either Flip Charts or Overhead Transparencies
- ___ Flip Chart Stand
- ___ Incentives for Participation in Methods of Communication Activity

Section 3

- ___ Prepared Overhead Transparencies / Flip Charts
- ___ Overhead Projector and Screen (optional)
- ___ Markers for Either Flip Charts or Overhead Transparencies
- ___ Flip Chart Stand

Section 4

- ___ Handouts
- ___ Enough of the Easy and Hard Version of the XYZ Tests (Equal Number of Each) for All Participants
- ___ Method for Dividing Participants into Groups of Equal Number (for the "All Kids Like Cookies" Activity)
- ___ Directions for Each Station
- ___ Props for the "All Kids Like Cookies" Activity

Vision Station: several pairs of prepared sunglasses, blindfolds, a page out of a coloring book or a crossword puzzle, crayons, children's books and magazines, plastic cup and pitcher with water, paper towels

Speech Station: marshmallows, gauze, trash can, paper towels

Fine Motor Station: several pairs of thick gloves, masking tape, puzzles, small manipulative toys, thick string and beads or pasta

Gross Motor Station: two large balls, two retrievable toys, masking tape, use masking tape to make two ten to fifteen foot walkways

Section 4, continued

- ___ Prepared Overhead Transparencies / Flip Charts
- ___ Overhead Projector and Screen (optional)
- ___ Markers for Either Flip Charts or Overhead Transparencies
- ___ Flip Chart Stand

Section 5-F

- ___ Overhead Transparencies / Flip Charts Developed by Trainers (optional)
- ___ Overhead Projector (if needed)
- ___ Flip Chart Stand (if needed)

Section 5-C

- ___ Prepared Overhead Transparencies / Flip Charts
- ___ Overhead Projector
- ___ Flip Chart Stand

Section 6-F

- ___ Overhead Transparencies / Flip Charts Developed by Trainers (optional)
- ___ Overhead Projector (if needed)
- ___ Flip Chart Stand (if needed)

Section 6-C

- ___ Prepared Overhead Transparencies / Flip Charts
- ___ Overhead Projector
- ___ Flip Chart Stand

Section 7-F

- ___ Overhead Transparencies / Flip Charts Developed by Trainers (optional)
- ___ Overhead Projector (if needed)
- ___ Flip Chart Stand (if needed)

BEST COPY AVAILABLE



Workshop Materials, continued

Section 7-C

- ☐ Prepared Overhead Transparencies / Flip Charts
- ☐ Overhead Projector
- ☐ Flip Chart Stand

Section 8-F

- ☐ Overhead Transparencies / Flip Charts
- ☐ Developed by Trainers (optional)
- ☐ Overhead Projector (if needed)
- ☐ Flip Chart Stand (if needed)

Section 8-C

- ☐ Prepared Overhead Transparencies / Flip Charts
- ☐ Overhead Projector
- ☐ Flip Chart Stand
- ☐ Criminal History Release (optional)
- ☐ Department of Social Services Check (optional)
- ☐ Stamped Return Envelopes (optional)

Section 9-F

- ☐ "Add My Name" Family Directory

Section 9-C

- ☐ Overhead Transparencies / Flip Charts
- ☐ Developed by Trainers (optional)
- ☐ Overhead Projector (if needed)
- ☐ Flip Chart Stand (if needed)

Section 10

- ☐ Caregiver Profile Form for Each Participant

Final Activity

- ☐ Prepared Overhead Transparencies / Flip Charts
- ☐ Overhead Projector
- ☐ Flip Chart Stand

Wrap Up

- ☐ What Did You Think?
- ☐ Comfort (Post)
- ☐ Knowledge (Post)
- ☐ Certificates

General Supplies to Bring

- ☐ Masking Tape
- ☐ Scissors
- ☐ Markers for Name Tents
- ☐ Play Doh (optional)
- ☐ Sticky Pads (optional)
- ☐ Other Table Supplies for Participants
- ☐ Candy or Other Energizer (optional)



Partners Plus Workshop

Childcare Information

We will be caring for your child at the Partners Plus Workshop scheduled for: _____. Please help us know more about your child:

Child's Name: _____ Date of Birth: _____

Routine at Home—Wake Time: _____ Meal Times: _____

Naptime: _____ Bedtime: _____

His / Her Special Abilities: _____

Favorite Toys or Playthings: _____

Favorite Foods / Any Allergies? _____

Favorite Games, Activities, Songs: _____

What Quiets Him / Her? _____

What Scares Him / Her? _____

What Excites Him / Her? _____

Names and Ages of Brothers or Sisters, if any: _____

Familiar Names (Friends, Family, Pets): _____

Any Concerns About Your Child? _____

How Can We Help? _____



Permission for Videotape with Sound/Photograph Use

I ☐ Do ☐ Do not (check one) give permission for me
and/or my child, to be filmed on videotape with sound to be used for
public information and publicity about the Partners project.

I ☐ Do ☐ Do not (check one) give my permission for me
and/or my child, to be photographed for informal pictures to be used
for dissemination materials for the Partners project.

Permission is applicable from the date signed to: _____

Signature: _____

Relationship to child: _____

Date: _____



Permission to Release Caregiver Name

How to use this sample form:

Prior to listing a caregiver's name in any publication (e.g. the Caregiver Directory), they will need to give permission for the release of their personal information.

I ☐ Do ☐ Do not (check one) give my permission for Partners to share my name and phone number with families interested in finding respite care. I understand that Partners will perform a criminal record check before adding my name to the caregiver directory.

I would like the following information to be added to the Caregiver Directory:

Name: _____

Address: _____

Telephone: _____ Date: _____

Signature: _____



Permission to Include Information in Family Directory

How to use this sample form:

Prior to listing a family's name in any publication (e.g. the Family Directory), they will need to give permission for the release of their personal information.

Families wishing to meet other families who have children with special needs may want to be included in the Partners Family Directory. The Directory can serve as a networking tool which allows families to meet other families and possibly exchange respite services with other interested families.

I would like the following information to be added to the Partners Family Directory:

Name: _____

Address: _____

Telephone: _____

Child's Age and Special Needs: _____

Sibling's Age(s): _____

Signature: _____ Date: _____



Partners Plus Order Form for Printed Materials

Name: _____

Title, Company: _____

Street Address: _____

City, State, Zip: _____

Telephone: _____ Fax: _____

Quantity	Item Number/ Description	Unit Cost	Total

Subtotal _____

Shipping and Handling _____

Total _____

Method of Payment:

Check number: _____ P.O. number: _____

Visa or Mastercard number (\$25 Minimum Charge): _____

Expires: _____ Signature: _____

Shipping and Handling Charges:

Orders totalling \$1.00 to \$49.99	\$7.00	Additional Fees required for international and priority delivery service
Orders totalling \$50.00 to \$99.00	\$10.00	
Orders totalling \$100.00 or more	\$12.00	

Return Completed Form To:

Child Development Resources, 1490 Government Road, Williamsburg, VA 23185
Phone (757) 220-1168 · Fax (757) 253-1779 · Email: ppcdr@tni.net

5

Section 5

measuring

your success

Measuring Your Success

Measuring Your Success

The purpose of evaluating your Partners program is twofold: documentation of activities and measurement of program impact. Program evaluation is a continual process of monitoring the quality of services and accomplishments. Efficacy data can be compiled and presented to program staff, families, caregivers, funding sources, and other community groups to build support for your program.

Partners Plus developed an evaluation system to determine the effectiveness of the model by collecting some simple data on the numbers of families and caregivers participating and the quality of the six-hour workshop. In addition, measures were developed to determine the efficacy of the project in increasing respite options.

If your Partners program plans to collect evaluation data, then you must first decide what you want to measure and who the audience is for your evaluation results.

Your program may want to consider three central evaluation questions.

- ***What did we do? (e.g. Who did we serve? How many workshops were held etc.?)***
- ***What were the outcomes? (i.e., Did respite options increase for families? Did caregiver knowledge and comfort increase?)***
- ***How satisfied were the participants? (i.e. What did families and caregivers think about training and technical support?)***



Measuring Your Success

Once you have decided what you want to measure, you'll need to consider how that information will be collected. Consider using:

- written surveys
- telephone interviews

Your program may want to collect descriptive information about the families and caregivers you support i.e., the age of the child, family/caregiver educational background, etc.

Sample instruments are included in Section 6. You may choose to use and/or modify these evaluation instruments to meet the needs of your program.

- ***What Did You Think About the Training?*** This instrument is used at the end of the six-hour training to gather numerical data and narrative comments about the quality of the workshop content, process, and trainers.
- The ***Initial Family Survey*** is designed to measure a family's respite options prior to Partners training and also collects demographic information. This survey can be conducted over the telephone, through the mail, or at the beginning of the workshop. When given more than once, it can measure a change in respite options over a period of time.
- The ***Follow-up Family Survey*** is designed to determine if families respite options increased as a result of Partners training. It is completed via mail or telephone after participating in the Partners workshop.



Out-of-Home Respite

- The *Caregiver Knowledge and Caregiver Comfort Scale Pre and Post* evaluations are used to measure caregiver knowledge and comfort levels as a result of Partners workshops. These are completed before and after the six-hour workshop.
- The *Follow-up Caregiver Survey* is used to measure if the personalized training has increased the caregivers' comfort level. These are completed via mail or telephone after attending the Partners workshop.



6

Section 6

sample evaluation
instruments

Sample Evaluation Instruments

Sample Evaluation Instruments

- What Did You Think About the Training?
- Initial Family Survey
- Follow-up Family Survey
- Follow-up Caregiver Survey
- Caregiver Knowledge Pre/Post
- Caregiver Comfort Scale Pre/Post



What Did You Think About the Workshop?

Name: _____ Date: _____

Presenter(s): _____

1. What I liked about the workshop...

2. How Did We Do? The information presented was:

_____ easy to understand

_____ difficult to understand because...

3. The information presented was:

_____ useful

_____ not useful because...



Partners Plus Initial Family Survey

Please describe any special needs your child might have. If you have more than one child, you may use the space on the back.

Child's Name: _____ Age: _____

1. Does your child have any special needs such as: developmental delay, multiple disabilities, vision, hearing, feeding, behavior, heart problems, breathing problems, other? If so, please explain.

2. Has your child received early intervention, special education, or therapeutic services? If so, please explain.

3. Does your child use any assistive technology such as: electric wheelchair, medical equipment, communications board, other? Please describe.



Initial Family Survey continued

Answer the following questions if you have ever left your child in another person's care. Please circle the best answer.

- | | | | | | |
|--|-----------------------|------------------|-------------------------|----------|---------------------|
| 4. In general, how hard has it been to arrange respite (temporary child care) for your child(ren)? | Not Difficult
1 | 2 | Somewhat Difficult
3 | 4 | Very Difficult
5 |
| 5. How comfortable did you feel leaving your child(ren) with the caregiver? | Not Difficult
1 | 2 | Somewhat Difficult
3 | 4 | Very Difficult
5 |
| 6. Have you ever taught a caregiver to care for your child? | Yes | No | | | |
| 7. How much time did you spend teaching the person how to care for your child? | Less than
30 mins. | About
3 hours | Over
3 hours | | |
| 8. In the last three months, how often have you used respite care? | 0 | 1-3 | 4-6 | 6 and up | |
| 9. In the last three months, how often did you want respite, but could not find a caregiver? | 0 | 1-3 | 4-6 | 6 and up | |
| 10. In the last three months, how many times did caregivers cancel? | 0 | 1-3 | 4-6 | 6 and up | |

Please answer the following questions about your family members. This information is optional.

11. Child's Mother's Age _____ Child's Father's Age _____

12. What is the child's mother's highest level of education?

- | | |
|--|---|
| ☐ Middle School | ☐ College Graduate (4 years) |
| ☐ High School | ☐ Some Graduate School |
| ☐ Some College | ☐ Graduate Degree |

13. What is the child's father's highest level of education?

- | | |
|--|---|
| ☐ Middle School | ☐ College Graduate (4 years) |
| ☐ High School | ☐ Some Graduate School |
| ☐ Some College | ☐ Graduate Degree |



Partners Plus Follow-up Family Survey

Name: _____ Date: _____

If you have participated in the Partners workshop, please answer the following questions:

1. How long ago did you participate in the Partners workshop? _____ Months _____ Years

2. How helpful was the Partners workshop for finding caregivers?

Not Helpful			Somewhat Helpful		Very Helpful
1	2	3	4	5	

3. How helpful was the Partners workshop for teaching caregivers?

Not Helpful			Somewhat Helpful		Very Helpful
1	2	3	4	5	

4. How comfortable do you now feel leaving your child with someone else (a caregiver)?

Uncomfortable			Somewhat Comfortable		Very Comfortable
1	2	3	4	5	

5. Since the Partners workshop, have you found a caregiver?

_____ Yes _____ No

6. In the last three months, how often have you used respite care?

0	1-3	4-6	6 and up
---	-----	-----	----------

7. In the last three months, did you want respite, but could not find someone?

_____ Yes _____ No

8. In the last three months, how many times did caregivers cancel?

0	1-3	4-6	6 and up
---	-----	-----	----------



9. Are you having any of the following problems finding good care for your child(ren)?

- ☐ Caregiver would not care for your child(ren)
- ☐ Caregiver would not follow your instructions
- ☐ Caregiver had insufficient skills
- ☐ Caregiver would not handle emergencies
- ☐ Other (please specify):

10. How helpful was the **Family Manual**?

Not Helpful		Somewhat Helpful		Very Helpful
1	2	3	4	5

Thank You!

Please return this survey to:



Partners Plus Follow-up Caregiver Survey

Caregiver Name: _____ Date: _____

Part 1. Answer the following questions if you participated in the Partners workshop.

1. How long ago did you participate in the Partners workshop? _____ Months _____ Years

2. How well did the Partners workshop prepare you to work with children with special needs and their families?

Poorly Prepared		Somewhat Prepared		Very Prepared
1	2	3	4	5

3. Have you been matched with a family needing respite for their child?

_____ Yes _____ No

If more than one family, how many?

Number: _____

4. Did the family you worked with participate in the Partners workshop?

_____ Yes _____ No

If more than one family, how many?

Number: _____

5. Did the family provide you with individual training specific to their child?

_____ Yes _____ No

If more than one family, how many?

Number: _____

Part 2. Answer the following questions if you cared for a child with special needs since the Partners workshop. If not, please continue to Part 3.

1. How many times have you provided respite care for a child with special needs since the Partners workshop? _____ 1-3 Times _____ 4-6 Times _____ 7 or More

2. How many different children with special needs have you provided care for since the Partners workshop? _____ number of children



Follow-up Caregiver Survey, Part 2 continued

Please describe the child(ren) you provide care for and his/her special needs.

Child: _____ Child: _____ Child: _____

Child's Age			
Services Received such as: - early intervention - special education - therapies			
Special Needs such as: - development delay - multiple disabilities - vision - hearing - feeding - behavior - heart - breathing - other			
Assistive Technology such as: - electric wheelchair - medical equipment - communication board - other			



Follow-up Caregiver Survey continued

Part 3. Please circle the number that best describes how comfortable you feel in working with children with special needs.

How comfortable are you:

	Uncomfortable		Somewhat Uncomfortable		Very Comfortable
1. Providing care for a child with special needs.	1	2	3	4	5
2. Planning activities that a child with special needs can enjoy.	1	2	3	4	5
3. Meeting the routine health care needs of a child with special needs.	1	2	3	4	5
4. Feeding a child with special needs.	1	2	3	4	5
5. Talking with families of children with disabilities about their child and their child's strengths and needs.	1	2	3	4	5
6. Talking to other people about any concerns they may have about children with special needs in your care.	1	2	3	4	5
7. Identifying resources and getting help you may need in caring for children with special needs.	1	2	3	4	5

Thank You !



Partners Plus Community Planning Manual
Child Development Resources
P.O. Box 280, Norge, Virginia 23127

DRAFT 10.99

6-11

Partners Plus Caregiver Knowledge Pre Evaluation

Name: _____ Date: _____

This survey is designed to gather information about your experience and knowledge of caring for children with disabilities or special needs.

Read each statement and circle the single best answer.

1. Early intervention services are available to children with disabilities who are
 - a. Birth to three years old
 - b. In public schools
 - c. Three to five years old
 - d. I don't know
2. Children who receive early intervention special education services must
 - a. Get therapy
 - b. Go to a classroom program
 - c. Have an individual plan
 - d. I don't know
3. All children with special needs receive education through
 - a. MCH
 - b. CHIP
 - c. IDEA
 - d. I don't know
4. Which of these diagnoses tells you that a child has a special health care need?
 - a. Autism
 - b. Cystic Fibrosis
 - c. Mental retardation
 - d. I don't know
5. Providing good respite care for a child with a disability depends heavily on
 - a. Desire/attitude of caregivers
 - b. Educational level of the caregiver
 - c. A child's disability
 - d. I don't know
6. When caring for children with disabilities in their homes, it is necessary to
 - a. Learn about their daily household routines
 - b. Change things to suit your way of providing care
 - c. Ignore the way the family trained you to take care of the child
 - d. I don't know



7. A key to a successful respite care program for families is
 - a. Providing each family with many caregivers
 - b. Allowing each family to train their own caregivers
 - c. To start more respite agencies
 - d. I don't know

8. It is most important for respite caregivers to
 - a. Understand child development
 - b. Know the needs of the child or children in their care
 - c. Have a degree or certification
 - d. I don't know

9. The term "cognitive development" is used to describe how a child
 - a. Relates to others
 - b. Sits and grasps toys
 - c. Thinks and solves problems
 - d. I don't know

10. If caregivers have questions or concerns about a child's special needs, they should
 - a. Discuss their concerns with the child's parent(s) or guardian
 - b. Call the local special education program
 - c. Not do anything because if they are wrong it would upset the child's parents
 - d. I don't know

Thank You!



Partners Plus Caregiver Knowledge Post Evaluation

Name: _____ Date: _____

This survey is designed to gather information about your experience and knowledge of caring for children with disabilities or special needs.

Read each statement and circle the single best answer.

1. Early intervention services are available to children with disabilities who are
 - a. Birth to three years old
 - b. In public schools
 - c. Three to five years old
 - d. I don't know
2. Children who receive early intervention special education services must
 - a. Get therapy
 - b. Go to a classroom program
 - c. Have an individual plan
 - d. I don't know
3. All children with special needs receive education through
 - a. MCH
 - b. CHIP
 - c. IDEA
 - d. I don't know
4. Which of these diagnoses tells you that a child has a special health care need?
 - a. Autism
 - b. Cystic Fibrosis
 - c. Mental retardation
 - d. I don't know
5. Providing good respite care for a child with a disability depends heavily on
 - a. Desire/attitude of caregivers
 - b. Educational level of the caregiver
 - c. A child's disability
 - d. I don't know
6. When caring for children with disabilities in their homes, it is necessary to
 - a. Learn about their daily household routines
 - b. Change things to suit your way of providing care
 - c. Ignore the way the family trained you to take care of the child
 - d. I don't know



7. A key to a successful respite care program for families is
 - a. Providing each family with many caregivers
 - b. Allowing each family to train their own caregivers
 - c. To start more respite agencies
 - d. I don't know

8. It is most important for respite caregivers to
 - a. Understand child development
 - b. Know the needs of the child or children in their care
 - c. Have a degree or certification
 - d. I don't know

9. The term "cognitive development" is used to describe how a child
 - a. Relates to others
 - b. Sits and grasps toys
 - c. Thinks and solves problems
 - d. I don't know

10. If caregivers have questions or concerns about a child's special needs, they should
 - a. Discuss their concerns with the child's parent(s) or guardian
 - b. Call the local special education program
 - c. Not do anything because if they are wrong it would upset the child's parents
 - d. I don't know

Thank You!



Partners Plus Caregiver Comfort Scale Pre Evaluation

Please circle the number that best describes how comfortable you feel in working with children with special needs.

How comfortable are you:

	Uncomfortable		Somewhat Uncomfortable		Very Comfortable
1. Providing care for a child with special needs.	1	2	3	4	5
2. Planning activities that a child with special needs can enjoy.	1	2	3	4	5
3. Meeting the routine health care needs of a child with special needs.	1	2	3	4	5
4. Feeding a child with special needs.	1	2	3	4	5
5. Talking with families of children with disabilities about their child and their child's strengths and needs.	1	2	3	4	5
6. Talking to other people about any concerns they may have about children with special needs in your care.	1	2	3	4	5
7. Identifying resources and getting help you may need in caring for children with special needs.	1	2	3	4	5

Thank You !



Partners Plus Caregiver Comfort Scale Post Evaluation

Caregiver's Name: _____ Date: _____

Please circle the number that best describes how comfortable you feel in working with children with special needs.

How comfortable are you:

	Uncomfortable		Somewhat Uncomfortable		Very Comfortable
1. Providing care for a child with special needs.	1	2	3	4	5
2. Planning activities that a child with special needs can enjoy.	1	2	3	4	5
3. Meeting the routine health care needs of a child with special needs.	1	2	3	4	5
4. Feeding a child with special needs.	1	2	3	4	5
5. Talking with families of children with disabilities about their child and their child's strengths and needs.	1	2	3	4	5
6. Talking to other people about any concerns they may have about children with special needs in your care.	1	2	3	4	5
7. Identifying resources and getting help you may need in caring for children with special needs.	1	2	3	4	5

Thank You !



7

Section 7

resources

Resources for Community Programs

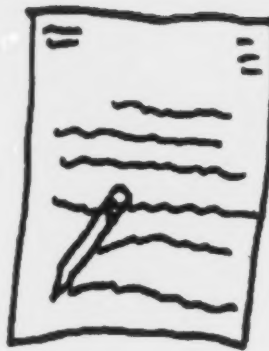
Resources for Creating a Community Respite Program

The following are helpful resources that may be used in conjunction with planning and developing your Partners program.

Access to Respite Care and Help (ARCH). (1992). *Respite care for children with developmental and/or physical disabilities: A parent's perspective*. Chapel Hill, NC: Author.

The National Council on the Aging, Inc. (1994). *Bringing family friends to your community: A replication manual*. Washington, DC: Author.

Dellinger-Wray, Molly & Uhl, Monica. (1996). *A practical guide to respite for your family*. Richmond, VA: Virginia Commonwealth University, Virginia Institute for Developmental Disabilities, The Respite Resource Project.



References for Board and Committee Development

If your Partners program is governed or advised by a board or committee, the following resources may support those board and committee members in carrying out their work.

Resources for Community Programs

Allender, Donna A. & Robert. (1982). *I am a member of the board*. New York, New York: Big Brothers/Big Sisters of America.

While aimed specifically at Big Brothers/Big Sisters, this two-volume notebook is adaptable to many other voluntary associations. It includes a leader's guide for persons who have responsibility for staff and board training relative to the work of the board.

Areas covered are leadership styles, committee structure, agenda setting, conducting meetings, taking and reporting minutes, the nominating process, duties of officers, and board development.

Andringa, Robert C. & Engstrom, Ted W. (1997). *Nonprofit board answer book: practical guidelines for board members and chief executives*. Washington, D.C.: National Center for Nonprofit Boards.

Andringa and Engstrom, who collectively have more than 70 years of experience as chief executives, board members, and facilitators in the training of more than 20,000 board members in 20 countries, take a closer look at the practical aspects of nonprofit governance, including formulating board structure and process, developing a strong partnership between board and staff, structuring effective board and committee meetings, and other critical issues.



Resources for Community Programs

Antes, Earl, Cronin, Jerry, & Jackson, Michael (Eds.).
(1985). *The nonprofit board book: strategies for
organizational success*. West Memphis, Arkansas:
Independent Community Consultants.

Twelve experts in various aspects of boardsmanship share
their expertise on the board and the life of the organization
in three major sections: overview of the board, organizing
the board, and tasks and essential concerns of the board.

Conrad, William R. & Glenn, William R. (1983). *The
effective voluntary board of directors: what it is and
how it works*. Athens, Ohio: The Swallow Press, Inc.

Conrad and Glenn present clear answers, backed by
graphics, to questions such as a definition of mission,
policy formation, functions of boards and staff, roles of
board members and the Chief Executive Officer, why
people join boards, and evaluation of board members.
Also presented is a basic management concept for
voluntary organizations.

Dyer, Delwyn A. & Williams, Oscar M. (1985).
*Developing effective and efficient local
committees*. Blacksburg, Virginia: Extension
Division, Virginia Polytechnic Institute and State
University (Extension Publication #301-023).

A monograph from the same series as "Developing
Effective Boards, Councils and Commissions." Detailed
explanation of committee purpose and function and
specific responsibilities of both the appointing body and
committee members.

Resources for Community Programs

Glenn, William E., Conrad, William R., Jr. (1976). *The effective voluntary board of directors: what it is and how it works*. Athens, OH: The Swallow Press, Inc.

Persons who serve on voluntary governing or advisory boards will find this book important reading. It offers a clear management concept and system appropriate to the unique challenges of voluntary organizations together with much practical application.

Herman, Robert D. & Van Til, Jon (Eds.). (1989). *Nonprofit boards of directors: analyses and applications*. New Brunswick, New Jersey: Transaction Publishers.

A compendium of research studies on board make-up and fund-raising success, board-member expectations, board member participation, women and boardsmanship, board/staff roles in management, and the planning and implementation of programs.

Hirzy, Ellen Cochran. (1993). *Nonprofit board committees: how to make them work*. Washington, D.C.: National Center for Nonprofit Boards.

This pamphlet was written to give you a better understanding of the effectiveness of nonprofit organizations and how you can strengthen the capacities of their leadership.



Resources for Community Programs

Holmgren, Norah. (1994). *10 minutes to better board meetings*. San Francisco, CA: Planned Parenthood Federation of America.

This booklet is designed to help you improve the quality of board meetings you attend either as a leader or a participant by offering guidelines for planning, participating, and leading.

Houle, Cyril O. (1989). *Governing boards: their nature and nurture*. San Francisco, California: Jossey-Bass.

Houle outlines in detail the responsibilities of the board, the chief executive, and staff, and shows how these three units can divide important tasks and work together effectively to help organizations fulfill their missions. He describes strategies for structuring the board and improving overall board operation, showing how to bring out the best in board members, maximize each person's contribution, and help the board identify and achieve important goals.

O'Connell, Brian. (1985). *The board member's book: making a difference in voluntary associations*. New York, New York: The Foundation Center.

Based on extensive experience working with volunteer boards and serving on them, O'Connell has developed a practical guide on such topics as legal responsibilities; finding good board members; planning, budget and financial accountability; the role of the board president; board/staff relations; and fund-raising.

Resources for Community Programs

Overton, George W. (1993). *Guidebook for directors of nonprofit corporations*. Chicago, IL: Planning and Marketing, American Bar Association.

This guidebook was prepared to aid the director of a nonprofit corporation in performing his or her duties. It was written for anyone presently serving as such a director, as well as anyone contemplating such service.

Richards, Audrey (Ed.). (1980). *Board member trustee handbook*. San Francisco, California: Public Management Institute.

A loose-leaf notebook format with over 400 pages of text, work forms, checklists, etc., covering the areas of assessment, boardsmanship process, the board as managers of planning and evaluation, committees and meetings, the board and the community, and leadership and team building. (Permission to copy is given.)

Swanson, Andrew. (1988). *The collected board sense: common sense for nonprofit board members*. Rumford, Rhode Island: Community Services Consultants, Ltd.

This compendium of over 60 articles originally appeared in newsletters or newspaper columns. Swanson usually covers one topic per article. They are easy to read and to remember.



Local and National Resources

Local and National Resource—Boards, Councils, and Committees

The following are resources that may be helpful in creating and maintaining boards, councils, and committees. In addition, Better Boards programs are located in many communities and organized collaboratively by volunteer centers, United Ways, county or city cooperative extension offices, and community colleges. These groups offer workshops and conferences on boardmanship tailored to the needs of local organizations.

Center for Volunteer Development
Virginia Tech
Blacksburg, VA 24061-0150
(703) 231-7966

Department of Volunteerism
Commonwealth of Virginia
223 Governor Street
Richmond, VA 23219
(804) 786-1431

The National Center for Nonprofit Boards
1225 19th Street, N.W., Suite 340
Washington, DC 20036
(202) 452-6262

References on Adult Learning

References on Adult Learning

The following resources may be helpful to trainers conducting Partners workshops. Specific training tips are included in the **Workshop Facilitator's Manual** contained in *Families and Caregivers as Partners: A Guide to Family-Centered Respite Care*.

Aldred, D. (1984). The relevance of Paulo Freire to radical community education in Britain. *International journal of lifelong education* 3, 2, 105-113.

Brookfield, S.D. (1984). Self-directed learning: A critique of research and theory. *Proceedings of the adult education research conference*, 25. Raleigh, NC: North Carolina State University.

Brookfield, S.D. (Ed.). (1985). Self-directed learning: from theory to practice. *New directions for continuing education*, 25. San Francisco, CA: Jossey-Bass.

Freire, P. (1985). *The politics of education*. South Hadley, MA: Bergin and Garvey.

Knott, E.S. (1983). A philosophical consideration of the relevance of Paulo Freire for the education of older adults. *Lifelong learning research conference proceedings*, 4. College Park, MD: University of Maryland, Department of Agriculture and Extension Education.



References on Adult Learning

Knowles, M.S. (1980). *The modern practice of adult education: from pedagogy to andragogy* (2nd ed.). New York: Cambridge Books.

Lovett, T., Clarke, C., and Kilmurray, A. (1983). *Adult education and community action*. London: Croom Helm.

Lovett, T. (1984). Ulster people's college. *Community education network* 4, 6:6.

Nadler, L. (Ed.). (1984). *The handbook of human resource development*. New York: Wiley.

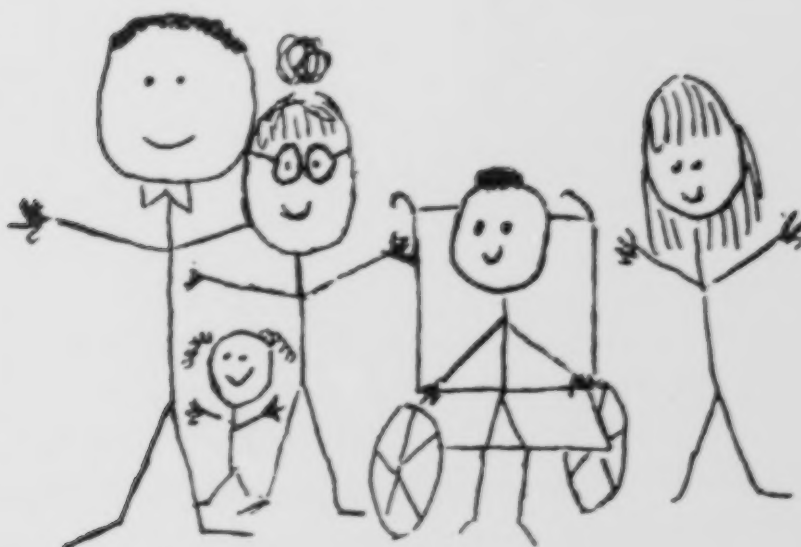
Peters, T.J. and Waterman, R.H. (1982). *In search of excellence: lessons from America's best-run companies*. New York: Harper.

Rossmann, M.H., Fisk, E.C., and Roehl, J.E. (1984). *Teaching and learning basic skills: a guide for adult basic education and developmental education programs*. New York: Teachers College Press.



Partners *Plus*

A Family Manual



Families and Caregivers in Partnerships
Child Development Resources

DRAFT 10.99

Partners *Plus*

Families and Caregivers in Partnerships: A Family Manual

By

Lisa L. Ownby, M.S.W.

Amanda C. Hooke, M.S.W.

Dee Wylie Moore, B.S.

Corinne W. Garland, M.Ed.

The Family Manual is part of a series of resources in the Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care. The rest of the series includes the Community Planning, Trainer's Workshop, and Caregiver Manuals, created by Child Development Resources.





Revised from the original

PARTners Plus: Parents as Respite Trainers Family Training Manual

Authors: Corinne W. Garland, Barbara A. Kniest, Karen S. McKinney, Dee W. Moore, and Nancy Tyree (1995)

Acknowledgments

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Amy Consiglio, of CM Consulting, designed and produced this manual.

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Funding to revise the Partners Plus guide to help families use existing community programs as respite for their school-age children with mental retardation came from the Joseph P. Kennedy, Jr. Foundation. Revisions to the manuals include practical "how to" information for personnel working with children in before- and after- school programs, recreational, camp, and other community programs.

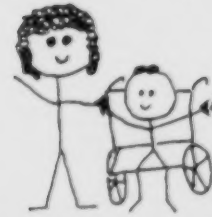
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Child Development Resources

Post Office Box 280

Norge, VA 23127-0280

Phone (757) 566-3300 / Fax (757) 566-8977



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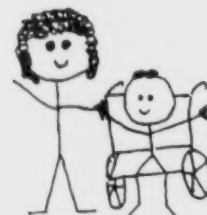
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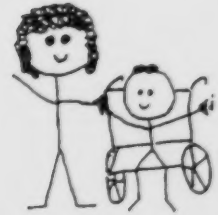
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- Step 2: List training methods
- Step 3: Use resources to help train your caregiver
- Step 4: Evaluation



Notes on this Section



Family Manual

introduction

Partners Respite Model

The Partners Model of Respite Care...

Helps families of children with special needs find and train their own respite caregivers.

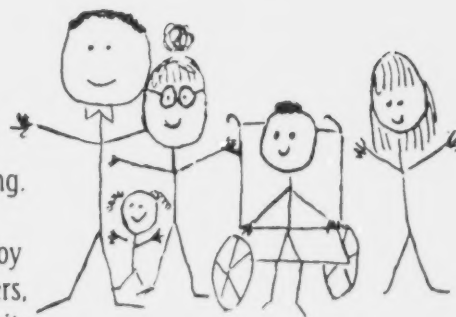
Through training and support, families and caregivers build long-lasting, successful respite relationships.

Introduction

Like all families, families of children with special needs want and need time away from the demands of parenting.

Respite—or temporary child care for children with disabilities or chronic illness—gives families time to enjoy an evening out by themselves, with other family members, or with friends. However, for these families, finding respite care is not as simple as calling a neighborhood babysitter. These families need caregivers who understand their children's special needs.

When the staff at Child Development Resources (CDR) spoke with families about what they wanted in a respite program, the message was clear. Families wanted to choose and train their own respite caregivers. They wanted affordable care that was as simple to schedule as calling the neighborhood babysitter. And, families wanted caregivers who were trained to provide care.



A Brief Partners History

In response to families and with support from the Virginia Institute for Developmental Disabilities (VIDD), a University Affiliated Program at Virginia Commonwealth University in Richmond, Virginia, CDR developed a pilot project that was low-cost, family-directed respite care called **PARTners: Parents As Respite Trainers**.

CDR was awarded, in 1994, a three-year grant from the U.S. Department of Education, Office of Special Education Programs (OSEP), Early Education Program for Children with Disabilities (EEPCD), to build on the pilot and to develop a model of respite that could be replicated in other communities. The project, **Partners Plus: Families and Caregivers in Partnerships**, provides a model for families to use in finding and training respite caregivers. This model encourages families to use available, **natural** family and **community** supports to meet their respite needs.

Within this model, Partners broadly defines the terms *respite* and *caregiver*. For example, respite can take place in a family's home, a caregiver's home, or in before and after school, recreation, camp, or other children's program. A caregiver can be any individual who *provides respite care* to a child with special needs or *includes* a child with special needs within an existing community program.

Partners Plus provided training to more than 200 families and caregivers in a five-city, three-county area of eastern Virginia. Partners usually conducted the six hour Partners Plus workshop for families and caregivers in one day. Sometimes when it was more convenient for a group, Partners conducted the workshop in two parts on separate days. This flexibility ensured that Partners adapted training



A Brief Partners History

to fit the schedules of families and caregivers who are generally most receptive to training during nontraditional hours such as evenings and Saturdays. Families attending the workshop learned to provide their own caregivers with personalized training based on their children's daily routines. Families either came to training with their own caregivers, met caregivers through the workshop, or through other project activities.

The Partners Project resulted in the development of four manuals designed to help communities, trainers, families, and caregivers use the Partners model. The **Family Manual** is one of four in a series of manuals that Partners has conveniently packaged together in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**. Besides the set of manuals contained in the guide, you can purchase the **Family and Caregiver Manuals** separately from the Partners Plus program through CDR.

Child Development Resources
Post Office Box 280
Norge, VA 23127-0280
Phone (757) 566-3300
Fax (757) 566-8977
Email ppcdr@tni.net

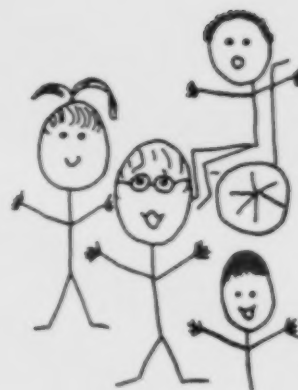
Partners Model: 5 Steps

The Partners Model: A New Model of Respite Care

Partners programs provide group training and continuing support to families and potential caregivers. The Partners model contains five steps:

The Five Steps of the Partners Model

- 1. Recruit Families and Caregivers*
- 2. Conduct Partners Workshop*
- 3. Help Families Choose Caregivers*
- 4. Guide Families as they Train their Own Caregivers*
- 5. Provide Continuing Support*



Step 1: Recruit Families

First, programs **recruit** families and potential caregivers to participate in Partners. Community awareness activities invite potential participants to a Partners workshop. Information about the workshop and the Partners program is distributed through parent groups, newspapers, radio, flyers, word of mouth, etc.



Partners Model: 5 Steps

Step 2: Conduct Partners Workshop

Next, programs *conduct the Partners workshop*. During the six-hour workshop, families learn how to find, screen, and interview caregivers for their children. In addition, they learn to structure training for their own caregivers based on the specific needs and daily routines of their individual children. Caregivers learn basic information about caring for children with special needs. During the workshop, caregivers are preparing to be active in their work with families, reflecting on their motivations for becoming respite caregivers and identifying their own learning needs for personalized training. Partners **Family and Caregiver Manuals** provide participants with useful resources to actively engage in during the workshop and to use as resources as they move through the next steps of the model.

Step 3: Families Choose Caregivers

After the workshop, Partners programs provide continuing support as *families choose caregivers*. Families frequently identify respite caregivers within their own circles of natural support. If families are unable to identify their own caregivers, Partners will assist by providing social and educational events that will help families and caregivers meet. During interviews, families and caregivers negotiate how respite occurs. Respite may be in-home or out-of-home and reimbursement for care can be flexible. Care may be provided for a fee, voluntarily, or in exchange for another service, such as yard work.



Partners Model: 5 Steps

Step 4: Families Train Caregivers

Once families and caregivers decide to work together, *families train their own caregivers*. This "personalized training," discussed during the workshop, is organized by families with help from Partners staff if needed. Families decide what routines caregivers need to learn and work with caregivers to determine how training will occur, thus forming true partnerships necessary for successful respite.

Step 5: Provide Continuing Support

As families and caregivers work together to develop a personalized respite training, the community Partners program *offers continuing support*, information and guidance. The Partners program is available to support families and caregivers in various ways as they begin their respite relationship. Partners staff members respond to requests for help and support from both families and caregivers. For example, Partners may help families and caregivers with screening, interviewing, developing personalized training plans, and providing educational opportunities.



Partners Replication Process

Partners Plus Replication Process

The Partners Plus **Community Planning Manual**, contained in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**, helps communities use the Partners model of respite care. Each community interested in model replication develops a plan for collaboration among agencies, organizations, and individuals in order to implement the model. Community resources and supports are needed to sustain the model, to create a home for the program, and to ensure continuation.

The community replication process includes four major steps:

- 1. Identifying the site for replication*
- 2. Planning for replication*
- 3. Implementing the model*
- 4. Evaluating the model*

The Partners Plus **Community Planning Manual** is a step-by-step guide for the replication process outlined in the flowchart on page xvi.

Your community will be a good candidate for replication if you have the following:

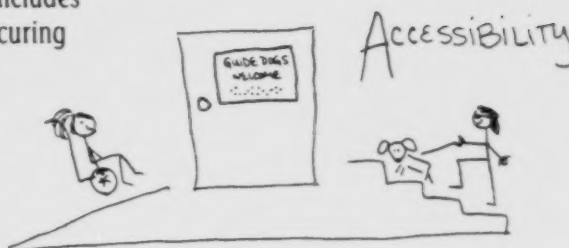
- support from agencies that provide, or are involved with, respite services



Partners Replication Process

- knowledge of current respite funding to support families without financial resources
- support and commitment from local early intervention programs, mental health or mental retardation programs, and/or family support programs

Each community needs to develop a **plan for replication**. Awareness activities aimed at a broad array of agencies, organizations, and individuals help strengthen community support. The creation of an advisory committee brings expertise and resources that will ensure a quality program. The replication plan includes finding a home for the program and securing staff responsible for implementing the program. Formal or informal interagency agreements and perhaps grant proposals may be necessary for community replication.



The **Community Planning Manual** provides strategies and materials to help communities develop and **implement** the respite care program. The **Trainer's Workshop Manual**, accompanying the **Community Planning Manual**, includes agendas, overheads, and suggestions for what to say during the Partners workshop. There are also suggestions for the kinds of resources that are needed by families and caregivers in order to foster and maintain long-term relationships.

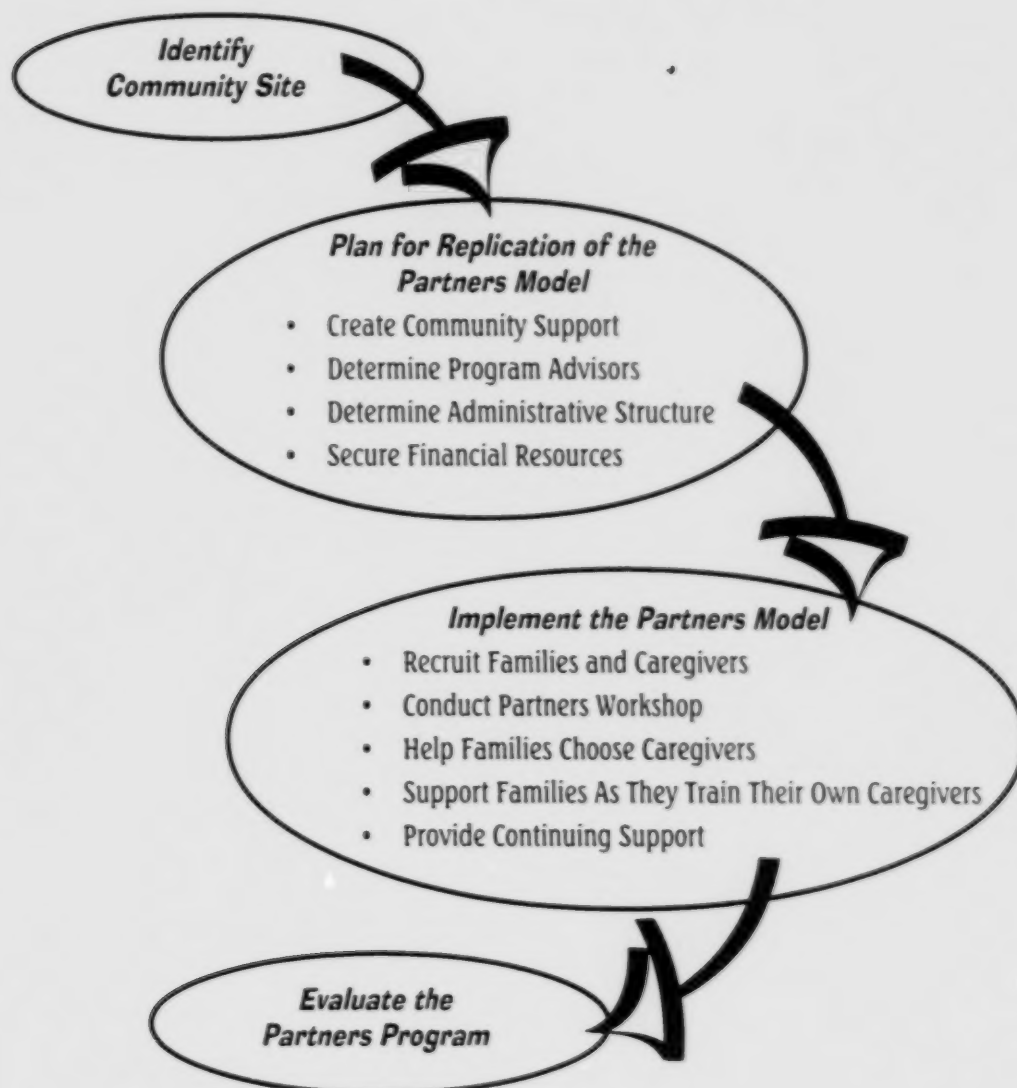
Communities that replicate the Partners model gather information from families and caregivers to **evaluate** the quality and usefulness of training and support.

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Partners in your Community

Partners Community Implementation Process



Partners Plus Manuals

Partners Plus Manuals

There are four manuals in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care** that support the Partners Plus replication process:

1. The **Family Manual**
2. The **Caregiver Manual**
3. The **Community Planning Manual**, and
4. The **Trainer's Workshop Manual**.

The **Family** and **Caregiver Manuals** are used in the Partners workshop for families and caregivers. These manuals include resources that families and caregivers can continue to use as they develop partnerships for respite care for children with special needs. The **Community Planning Manual** helps communities develop a community-based, family-centered respite system. The **Trainer's Workshop Manual** contains overheads, forms, and "helpful hints" for conducting Partners workshops.

The **Family Manual** is easy to follow and guides families in choosing and training their own respite caregivers. Families use their children's daily routines to develop training plans for caregivers. The manual includes information about respite, communication, building partnerships, selecting caregivers, and developing personalized training. There are worksheets, resources, and forms that can be duplicated for future use.



Partners Plus Manuals

The **Caregiver Manual** provides caregivers with basic information on caring for young children with disabilities and supporting families. This manual includes information about respite, communication, building partnerships, disabilities awareness, child development, children with special needs, and personalized training with families.

The **Community Planning Manual** provides communities with a step-by-step guide to replication of the Partners model. By following each step, communities and families can work together to develop respite care programs. The manual contains forms and materials to assist with replication of the model.

The **Trainer's Workshop Manual**, used in conjunction with the **Community Planning Manual**, helps community trainers to conduct the six-hour Partners workshop for families and caregivers.

1

Section 1

About respite

About Respite Care

Respite . . . Rest, Relax, Renew

Often we are asked, *What is respite care?* Our first response is simple: respite care is temporary care for a family member with special needs.

Families have told us in many different ways what respite means to them:

- Time to readjust.
- A break from the routine.
- Rest in spite of demanding circumstances.
- I feel refreshed and renewed when I come back from respite.
- Think of a candle that slowly burns: the flame flickers and goes out, and, just as a candle, we need to be relit, too.

— *Partners Plus Families*



More About Respite Care

Respite care is a term used to describe occasional care for an individual with special needs. Respite care programs began in the 1960s when people with disabilities began receiving care in their homes and communities instead of in institutions. Acknowledging the importance of respite care to families providing home care, Congress passed federal legislation providing funds to help communities develop respite care programs.



Who Needs Respite?

The 1986 federal legislation that provided funds to set up model programs of respite care defines respite care as in-home or out-of-home temporary, nonmedical care for families who have children (young and/or adults) with disabilities or chronic or terminal illnesses. More simply, respite care is any type of temporary care provided to a person with a disability or special health care need.

There are a variety of respite models, each designed to meet the unique needs of families. Descriptions of these models are included in Section 9 of this manual (see ARCH Fact Sheet Number 2).

Families Who Need Respite

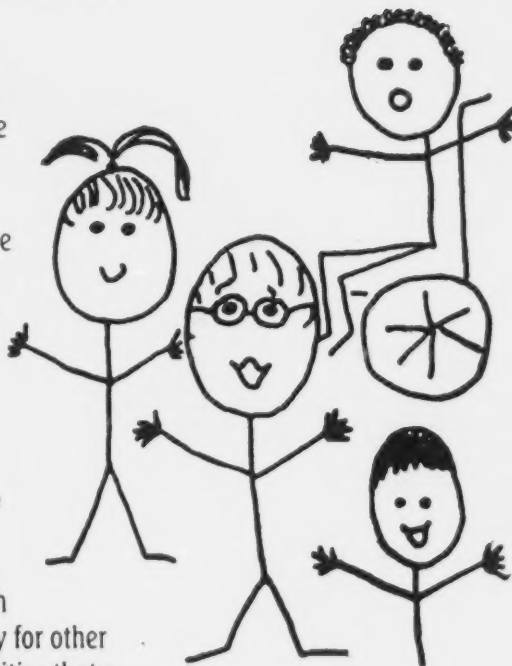
Families who have children with special needs are very much like other families. Like all families, they have values, beliefs, interests, concerns, needs, and dreams. However, families of children with special needs also have special challenges that affect the way they live. Here are some things we have learned from families.

- Like other parents, parents of children with special needs are concerned about their children's
 - development,
 - health,
 - education,
 - training, and
 - social life.
- Parents of children with special needs must put forth extra effort to help their children.



Who Needs Respite?

- Parents of children with special needs are often very knowledgeable about their children's disabilities and have learned some of the best ways to help them.
- Like other parents, parents of children with special needs are concerned about
 - the needs of all of their family members,
 - the education of all of their children,
 - the activities of all of their family members, and
 - their jobs.
- Daily routines for families of children with special needs are similar to those of other families.
- Families of children with special needs have hopes and dreams that are like those of most other families.
- Children with special needs and their brothers and sisters can grow up healthy and lead productive lives.



Children Who Need Respite Care

A child who needs a respite caregiver is one who has special physical, emotional, or health needs that require care beyond that necessary for other children. The kinds of special needs or disabilities that a child may have can vary greatly from hearing impairments that require a child to communicate through sign language to mental retardation to terminal illness.



Benefits of Respite Care

There is no one approach to caring for children with special needs but there are some basic guidelines:

- Children with special needs are more like other children than they are different.
- Children with special needs can and do learn.
- Children with special needs should be encouraged to do as much for themselves as they can.
- Children with special needs thrive when given love, acceptance, and necessary support.
- Like other children, children with special needs benefit from healthy play and recreation, friendships, being outdoors, and going places.

Benefits of Respite to Families

Respite care gives parents a break from the daily demands of parenting a child with special needs, and offers much more.

Rest to recuperate, rejuvenate, replenish, rejoice

Enjoying movies, dinner, fishing

Shopping for groceries, school, self, kids, family

Pampering at a hair salon or gymnasium or having lunch with a friend

Interests to pursue such as hobbies, sports, community activities, and education

Time to spend with siblings, other family members, and friends

Everything or **anything** families want to do!



Benefits of Respite Care

Benefits of Respite to Children

Respite is also beneficial to children. Some of these benefits include the following:

- Relief that their parents finally got out
- Exploring new faces and activities
- Special friends of their own
- Parents who feel rejuvenated
- Interacting with other adults and children
- Time to be independent from their family
- Educating each other about differences and similarities

Benefits of Respite to Caregivers

Respite also benefits caregivers in many ways.

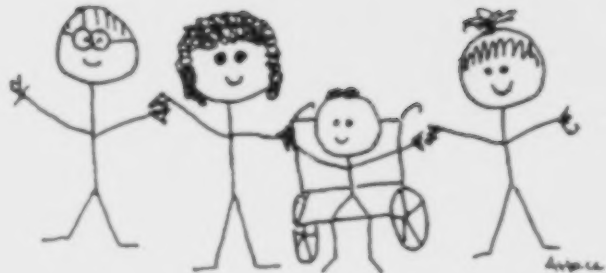
- Really great children and families to get to know
- Especially rewarding to know that they are making a positive difference for a family
- Self-improvement and growth through learning new skills and ideas
- Positive attitudes about themselves and about people who are different from themselves
- Involvement with children, families, and communities
- Thoroughly appreciated by families who need them
- Everything caregivers want respite to be!



Barriers to Respite Care

Who Can Be Respite Caregivers?

- Neighbors
- Friends
- Relatives
- Community Program Staff
- Church Members
- Students
- Bus Aides
- Anyone with a desire



Why Don't Families Use Respite Care?

Despite the benefits of respite for everyone, many families do not use respite care. Families have identified various reasons:

- It is difficult to find someone to provide temporary care.
- We are afraid to leave our children with strangers.
- We fear that respite caregivers lack adequate training.
- We sometimes feel guilty about leaving our children.
- It is difficult to find community programs for respite care.
- It is too disappointing when caregivers cancel frequently.



Keys to Successful Respite

Keys to a Successful Respite Program

Families say a successful respite program must have these elements:

- Helps families feel comfortable
- Gives families options for how they want to participate
- Gives families options for times to be involved
- Is family centered
- Supports families in developing new linkages
- Supports families in developing individualized caregiver training
- Asks families if they want to be involved in program planning
- Gives families access to dependable, reliable caregivers

Source:

Reprinted with permission of ARCH National Respite Network and Resource Center, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514:

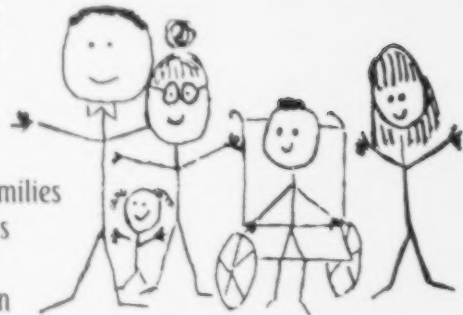
Access to Respite Care and Help (ARCH). (1992). *Respite care for children with developmental and/or physical disabilities: A parent's perspective*. Chapel Hill, NC: Author.



Describing Family-Centered

Description of *Family*

What Do We Mean by Family? We all come from families. Families are big, small, extended, nuclear, multigenerational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, or as permanent as forever. We become part of a family by birth, adoption, marriage, or from desire for mutual support. As family members, we nurture, protect, and influence each other. Families have strengths that flow from individual members and from the family as a whole. Each family is a culture unto itself, with unique values and its own way of realizing dreams. Together, our families are the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states, and nations.



Source:

New Mexico Children's Continuum/New Mexico Advocates for Children and Families. (1990). *First steps to a community*. Albuquerque, NM: Author.

Description of Family-Centered Philosophy

Family centered means the recognition that the family is the constant in a child's life and that service systems and the personnel must support, respect, encourage, and enhance the strengths and competence of the family.

Source:

Shelton, T., Jeppson, E., & Johnson, H. (1987). *Family-centered care for children with special health care needs* (2nd ed.). Washington, D.C.: Association for the Care of Children's Health.



Family-Centered Care

Family-Centered Care

What does providing family-centered care mean?

- Recognizing that a family will always be in a child's life while services and professionals will change
- Making it easier for families, volunteers, and professionals to work together in hospitals, homes, and community care
- Sharing information, ideas, and concerns among families, volunteers, and professionals as a team
- Honoring the diversity of families, knowing that we each bring richness to the world we live in through our cultures and the ways we live our lives
- Recognizing and respecting that families meet their own needs in different ways
- Designing services that are flexible, that are easy for families to use, and that meet each family's individual needs
- Appreciating families as families and children as children and recognizing that they have a wide range of strengths, concerns, emotions, and dreams beyond their needs for specialized health and developmental services and support



Source:

Reprinted with permission of the Association for the Care of Children's Health, 19 Mantua Road, Mt. Royal, NJ 08061:

Shelton, T. L., & Stepanek, J. S. (1994). *Family-centered care for children needing specialized health and developmental services*. Washington, DC: Association for the Care of Children's Health.



Partners Respite Model

A New Respite Model: Partners

The Partners model of respite care is designed to increase respite options for families of children with special needs by helping families find and train their own respite caregivers.

Respite can be provided in:

- Families' homes
- Caregivers' homes
- Community respite programs
- Before and after school programs
- Recreation programs
- Camps

Respite can take place anytime, any place, with anyone in order to support families in meeting their needs.

Partners is a natural and family-centered model that involves families in the design, implementation, and evaluation of respite care. The model encourages the development of community collaboration among agencies and parent, religious, and/or support groups to support this model and to create a home for the program.

Together, families and caregivers attend group training. Families learn how to recruit, screen, interview, and train caregivers. Caregivers are provided with basic education in caring for children with special needs. After group training, the next step is for families and caregivers to match up and begin individualized training. The **Family and Caregiver Manuals** are provided to families and caregivers to use as a resource to help them through this process.

Partners...

- *is a family-centered model.*
- *offers families many choices.*
- *allows families options for how they can participate.*
- *supports families in finding caregivers.*
- *supports families in training their own caregivers.*
- *helps families build necessary skills to communicate respite needs.*
- *helps families build long-term caregiver relationships.*
- *expands respite options for families.*



Partners Respite Model

The Partners program provides support to families and caregivers to help them begin building respite relationships. When a family cannot find a respite caregiver within their own circle of natural supports, they can choose from the pool of caregivers recruited by Partners Plus or can attend social and educational events coordinated by the program to help families and caregivers meet and match up.

With the Partners model, families and caregivers have choices about how respite care is provided. Respite may be provided in-home or out-of-home. Care may be provided for a fee, in exchange for another service, or by a volunteer. These decisions are made between families and caregivers. Families may also choose to develop a parent (or family) cooperative in which they care for each other's children. Families decide what kind of training caregivers need and work with caregivers to determine how training will proceed, forming a true partnership necessary for successful respite.

Partners Model of Respite Care

- Step 1 Recruit families and caregivers*
- Step 2 Conduct Partners workshop*
- Step 3 Support families in choosing caregivers*
- Step 4 Guide families as they train their own caregivers*
- Step 5 Provide continuing support*



2

Section 2

building partnerships:
communication

Building Partnerships: Communication

Building Partnerships

Respite care is not just about giving out medicine. It is a whole dialogue and relationship with a family.

— Partners Plus Caregiver

Partners Plus supports strong relationships between families who have children with special needs and their caregivers. In partnerships, families and caregivers respect one another and commit to working together.

Partnerships actively prevent caregiver burnout and family disappointment. Partnerships are built with open and honest communication and understanding. Sections 2 and 3 of this manual explore building partnerships through communication and collaboration.

Building Partnerships Through Communication

Good communication strengthens the relationship between family and caregiver.

Honesty and openness in communication help build cooperative relationships over time!

What does communication mean?

- *Sharing information, ideas, and feelings that increase understanding about yourself and others*
- *Listening carefully to each other in ways that develop partnerships and promote the best care for children*
- *Sharing common values and traditions and talking about similar experiences to strengthen your relationship with each other*
- *Appreciating differences to strengthen mutual respect*



Using More Than Words

Building Partnerships: Communication

Clear communication is one key ingredient in building partnerships. We send messages all the time, even when we are not speaking.

Communication is . . . 7% Words

Research shows the words we use or choose are important in gaining understanding. In communicating with another person, we need to use language that is common to both the speaker and the listener.

38% Voice

The voice we hear is more important than the words we use. We need to be aware of our expression and tone of voice. We use our voices to help express things like sincerity, conviction, requests, and concern.

55% Facial and Body Language

Our face and body are the most powerful means of communication. Smiles, frowns, raised eyebrows, widened eyes, tears, laughter, scrunched-up faces, and wrinkled noses all tell us very different things.



Source:

CareerTrack. (1992). *How to deal with difficult people: Video workbook*. Boulder, CO: CareerTrack Publications.



How Do You Feel?

How Do You Feel?

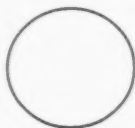
Facial expressions can communicate a lot about our thoughts and feelings. Use the blank circles to draw faces that send messages to others.



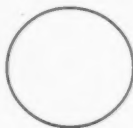
Anxious



Angry



Bashful



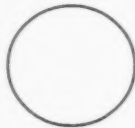
Bored



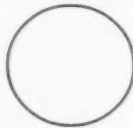
Confident



Thinking



Confused



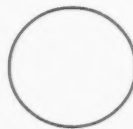
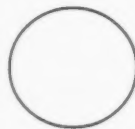
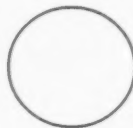
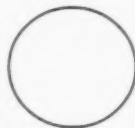
Scared



Innocent



Relieved



*Adapted from
feelings posters
by:*

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Today? Productions,
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Understand the Cycle

Six Messages of Communication

Communication is a cycle. As you communicate with others, think about the many places that communication can break down. Does the other person really understand what you mean? Each communication contains the possibility of six separate messages:

- What you mean to say
- What you actually say
- What the other person hears
- What the other person thinks he hears
- What the other person says
- What you think the other person says

Adapted from:

Bassett, L. C., & Metzger, N. (1986). *Achieving excellence: A prescription for health care managers*. Gaithersburg, MD: Aspen Publishers.

What You Need to Know About Communication

- **Communication is the way we send and receive messages.**

Most people use a combination of verbal and nonverbal communication. Being aware of and sensitive to the different ways people communicate helps to build mutual respect and understanding between families and caregivers.



Learning To Communicate

- **Our ways of communicating are influenced by our culture.**

Our culture determines much about how we think, feel, act, and communicate with others.

- **The term *life ways* refers to the many ways we are influenced by others and by our environment throughout our lives.**
- **Gestures, silence, body movements, distance, and emotional expressiveness are other ways of communicating that are influenced by our cultures and life ways.**

For Example:

- Too much silence makes some people uncomfortable.
- Too few pauses while talking may disturb others.
- To be comfortable, some people need some distance between themselves and others.
- Lots of eye contact is important in establishing trust for some.
- For others, too much eye contact is considered disrespectful.
- A relaxed open body posture, with arms not crossed in front, invites others to talk.
- Leaning slightly forward shows interest.
- Sitting up straight helps you look more alert.
- Much of our communication is done without words.
- Our eyes are used to communicate.



Connecting without Words

For Example:

A look can be exchanged between parents that says, *It's time to leave*, or a look from a mother's eyes to her child can communicate the message, *You need to behave*.

- **When people have similar experiences, we sometimes presume a shared understanding of feelings or thoughts.**

For Example:

When a parent at an oncology clinic says to another parent in the waiting area, *My child is receiving chemotherapy for leukemia too*, an exchange that takes place by looking at each other in the eyes can send a message of shared understanding, even though each family's experience is unique.

Depending on their life ways, families use more spoken or written words to communicate. Words help us to be direct, exact, and logical and encourage others to say more. The following is an example of a family and caregiver interview in which words are used to encourage a response.

Caregiver: I want to provide respite because I enjoy being with children.

Family: That's great! You like being with children.



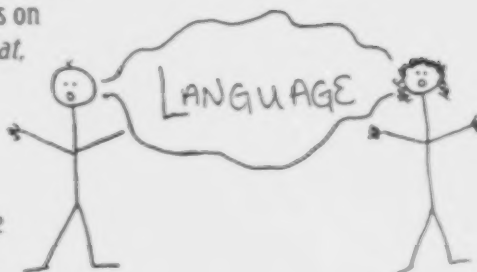
Methods of Communication

Caregiver: Yes, I miss being a parent and my grandchildren live in another state. When my children were young, I enjoyed planning activities for them.

Family: What type of activities do you like to plan for children?

- Spoken and written words are helpful in finding out about a person's feelings and attitudes.

Questions that cannot be answered with a yes or no encourage others to talk about what is on their mind. Use words like *how*, *why*, *what*, and *tell me*.



For Example:

Family: On your first visit to my home you watched me feed Crystal and I gave you some information to take home to read. Why don't you try feeding Crystal today?

Caregiver: I think I should watch again to make sure I remember how.

Family: You seem uncomfortable trying this now. Tell me about your concerns.

Caregiver: I remember how much Crystal coughed when you fed her and how much she gagged. I am afraid I will choke her. I think you need someone with nursing skills to take care of your child.



Matching Life Ways and Styles

Family: Perhaps we need to talk again about why Crystal has difficulty eating and why she might cough or gag. I want you to understand Crystal's special needs and to feel comfortable in caring for her. I am here to help while you feed her. Let me show you again. Then you try.

- Using words like *describe*, *show me*, and *tell me* can help determine if a caregiver has learned a skill or has understood the instructions.

For Example:

Family: How did your first day go?

Caregiver: I had trouble using Jared's wheelchair when we went outside.

Family: Tell me what gave you trouble.

Sharing Information

To ensure a successful respite relationship, families and caregivers need to openly share information. This is necessary in initial training and throughout the relationship.

Information can be shared in many ways:

- Keep and share a respite journal.
- Plan information you want to share when you get together.



Tips for Caregiver Interaction

- Allow time to meet with each other before respite care takes place.
- Allow time to talk after respite care.
- Make necessary decisions promptly.
- Resolve conflicts in a timely way.
- Solve problems together.

Tips for Communicating with Your Caregiver

- Communication is essential and is an important part of maintaining a successful relationship.
- Give clear instructions and make sure your caregiver understands what you have said.
- Provide immediate feedback to your caregiver during all training activities.
- Put yourself in the caregiver's place; remember, you once had to learn new ways to care for your child.
- Let your caregiver know when respite care goes well and when you are pleased.
- Be positive. When changes are necessary, tell your caregiver in a positive way.



3

Section 3

building partnerships:
working together

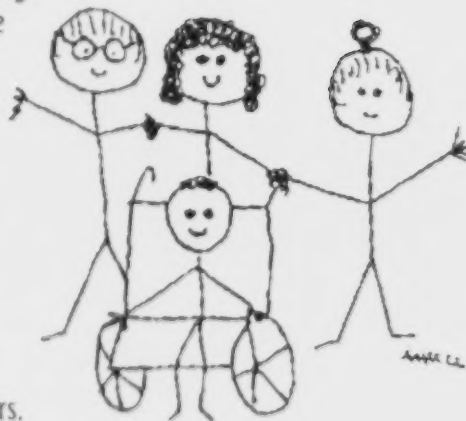
Partnerships: Working Together

Anyone with a desire to help families of children with special needs can become a capable respite caregiver. At first, many parents do not know how to care for their children with special needs, but gradually they learn. Through willingness to learn from families, respite caregivers can do the same.

Many respite caregivers, although not parents of children with special needs, can appreciate the benefits of getting a break from caring for children. Some people have life experiences that help them become more comfortable as respite caregivers. They may know someone who has special needs—a friend, a student, a classmate, someone at church, or a family member. The most important quality a respite caregiver has is a positive attitude.

We know children and their families depend on each other. Children depend on their families for love, support, and guidance. The family is a continuing influence in their child's life, whereas friends, neighbors, and caregivers change. Parents know their own children best. Families and caregivers need to know how to work together for successful respite care.

While caring for children with special needs can be a wonderful experience for both families and caregivers, it can also be stressful. It is helpful for families to understand the challenges that caregivers face when caring for children with special needs. Caregivers may feel unimportant or underappreciated. They may be uncomfortable with the tasks they are given. The material on the following pages can help you learn from each other.



One Family's Story

Family and Caregiver Perspectives

Families and caregivers can better understand each other by listening to personal experiences. Several perspectives from families and caregivers are included in this section.

The first story is "Welcome to Holland" by Emily Pearl Kingsley. From that story, you will see how one parent, whose child was born with a disability, saw her life changing. Other stories from families and caregivers are also included. Your story may look very different from these. To get a better understanding of one another we encourage families and caregivers in partnerships to share their unique stories.

"Welcome to Holland"

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . .

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans—the Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes in and says, "Welcome to Holland!"



"Welcome to Holland"

"Holland?!" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy!"

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people that you would have never met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for awhile you look around and you begin to notice Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned." The pain of that will never, ever, go away because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't go to Italy, you may never be free to enjoy the very special, the very lovely things in Holland.

— *Emily Perl Kingsley, 1981, Parent*



"A Personal Story"

A Personal Story

Although my son Matthew died, he is still a part of my life. Matthew made a difference in who I have become. At first I shared the same thoughts and feelings that Ms. Kingsley expresses in "Welcome to Holland." After Matthew was born, my family began to live a different kind of life. It was often very difficult for us. We learned a lot about ourselves and we learned a lot from Matthew. We discovered that our love for Matthew and each other was very powerful. We found that we had many hidden strengths. Our family grew stronger ties with our community. Friends, neighbors, professionals, and even strangers helped us in many different ways. There were two very important things we wanted most from others. One was for others to accept our son. The other was respect for our family's decisions in how to live with our child's chronic illness and disabilities.

After getting to know Matthew, his disabilities did not seem like the most important part of his life. My four-year old daughter taught me to love Matthew just because he was a baby. To my daughter, Matthew was always her baby brother, not a baby with disabilities. She never noticed much difference until she got older. Other families of children with disabilities have shared some similar thoughts with me. Many say they wish others would stop seeing only their child's wheelchair, their tubes, the way they talk differently or look different. At times, families want professionals to stop testing their



"A Personal Story"

child long enough to get to know him or her as a child, a child with a name and family.

When I describe my son, I tell people that Matthew was small and easy to carry places. Daily care for Matthew was like taking care of an infant. He had a crooked little smile. His sister could make him smile most often, but others could sometimes if they gave him a gentle squeeze around his shoulders. His favorite game was to repeat sounds that we made to him. Matthew's favorite toy was a baby's beaded teething ring. He liked to fall asleep on his father's shoulder. Matthew's greatest strength was that he could teach others about the power of the human spirit.

In describing Matthew's disabilities I would say that Matthew had a genetic impairment called trisomy 22. Trisomy 22 is an extra chromosome that affects every part of the body. He never grew to be more than five pounds and twenty-three inches. There was a hole in the roof of Matthew's mouth that made sucking and feeding very difficult. We fed Matthew with a tube that we put down his throat and into his stomach. His heart and all other systems in his body did not work well. Matthew was delayed in all areas of his development. With help from professionals we learned to deal with all of his special needs.

Getting information about our son's disability through an early intervention program and from medical practitioners helped us understand how to care for our child. A service that helped our family a



"Father of Child with Special Needs"

lot was respite care. My family and I needed time separate from being with Matthew. I wanted to give all my attention to my daughter at her soccer games. My husband and I needed time together to laugh and have fun. I needed time to rest physically from the frequent round the clock feedings required for Matthew. I needed emotional rest from the constant concerns I had for Matthew. A few friends, neighbors, and community agencies helped us get respite from time to time. One agency linked us with a community family who was willing to give me a few hours of respite each week. Just those few hours gave me the relief I needed to renew my energy and continue to care for Matthew.

— Dee Moore, 1995, *Parent*

Being a Father of a Child with Special Needs

Being a father of a special needs child takes a special person. There are times when you just want to give up but you know that you can't. The doctors gave my son 3 days to live and now my son is 3 years old. It's a blessing from God that he's still with me today. One thing that I try to remember is to treat him like a normal child. I take him to amusement parks on vacation and to the mall, just to name a few places.

There are times when it's very difficult being a father of a special needs child. I have to watch my



"Father of Child with Special Needs"

child go through intensive surgeries just to be able to eat and breathe like you or I. There are times when all you can do is just listen to your child cry uncontrollably, but overall being the father of a special needs child is a blessing from God. If you're a dad and wonder what it's like to be a dad to a special needs child, it is like taking care of three children.

— *Lamar Ramsey, 1997, Parent*

A Parent's Perspective

From the moment Kieren was born, I knew something wasn't quite right. He used to cry all the time. He was totally fearless, and I could leave him with anyone. He didn't seem to care if I was there or not. As he grew older, he used to run away all the time. We had to lock all the doors and never let go of his hand when we were out or he was gone and he didn't come back. If he saw something he liked, he would jump up and down, flap his hands, and shriek. Looking back, there were a lot of warning signs but I didn't know what I was looking for. I just knew that something was not right. I think one of the worst things about not knowing he had high-functioning autism was that no one else seemed to think there was a problem (or so they led me to believe). I would say to family and friends that I was concerned, and they would tell me, "Oh, all children do that," and dismiss it, and in the end I was beginning to doubt my sanity.



"A Parent's Perspective"

When he was 2, we were stationed in Germany, where 9 months later my daughter was born. I think it was a blessing in disguise that we were in that country as they test routinely for cystic fibrosis in all newborns. We found out when she was 6 weeks old that she had it. She was having some problems but the doctors told me this is normal, all babies do these things. Where have I heard that before?!

So we were sent back to the states so that we could get the health care she needed. Once she was relatively stable, I turned my attention back to Kieren. I made an appointment with the school division to get Kieren assessed to see if he was eligible for the special education program. During all the appointments I remember thinking he is doing really well today and they are going to think I'm crazy. As it turned out, he was eligible with significant delays in language, cognitive and fine motor skills.

He started the special education program, and things went relatively well for the first 6 months as Kieren's language started to emerge and he became a little more in control of his actions. I will never forget the first home visit I had with the special education teacher. She told me how Kieren didn't do this or that, wouldn't pay attention, kept flapping his hands, and wouldn't sit down and eat (tell me something I don't know!). During that visit I could hardly talk for fear of crying. I felt she was telling me what a lousy job I had done in bringing up my son. I blamed myself for a long time, thinking I should



"A Parent's Perspective"

have done something and he would be normal. I thought that the "experts" knew what they were talking about, and I tended to listen more to them than to my inner feelings.

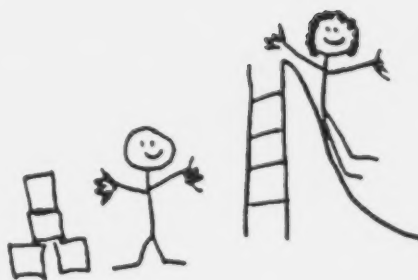
I am glad to say that now I know better. I listen to myself first, and then incorporate what the "experts" say into my plan. I've learned the hard way that parents are the experts on their child, and what's good for one child is not necessarily so for all children.

— *Itala Eller, 1997, Parent*

Malachi

I have a special sibling. My brother is intelligent and trusting and 2 1/2 years older than me. When we were little, we used to have bitter sock wars on laundry day, and he taught me all about dinosaurs (he knew a lot about dinosaurs). He drew these amazing, elaborate, creative pictures. I remember one called "War of the Grapes." It was a crayon picture of hundreds of little grapes in all kinds of armor and camouflage, and the red grapes were battling the green grapes. You looked at this picture and were amazed at the 7-year-old mind that constructed it.

Malachi also has a disability. For many years, my parents have been trying to figure out what disability it is. His symptoms have grown progressively worse since he was young, although,



"Malachi"

at times, some medications have given us hope for improvement. Malachi is painfully shy. While he learned to make eye contact, you wish he would stop, it seems so painful for him. To ask him a question, you need to get his attention, then repeat the question until he understands, and wait patiently for his answer. Malachi never asks the follow-up questions to statements, and he rarely involves himself in a conversation involving more than one person. He has trouble with directions. While he nods and indicates that he understands, he may not recall the conversation when it is time to carry the directions out. Malachi was slow to speak, and used a speech therapist for a time after he learned his first words.

Later, Malachi started talking to himself, repeating the same words over and over while he worked them out in his complicated brain. When he was a teenager, he started talking more roughly to himself, pounding his fist in the wall, having even more trouble focusing. His counselors don't know how to label him. At different times, he has been diagnosed with learning disabilities, speech delays, a perceptual disorder, pervasive developmental disorder, brain injury, mild mental retardation, depression, schizophrenia, and disassociative disorder. He doesn't fit into a neat little box. But who does? At this point, I give up. My parents, still trying to find services to help him and guidance for their work with him, need a diagnosis. Otherwise, how will he be eligible? How will they know what interventions to try next?



"Malachi"

When we were little, there was special education for Malachi, but he was intelligent, with no physical disabilities. The services offered to him were very limited. There was certainly no respite. When I turned 6, I entered public school with Malachi. My parents had recently gotten divorced, and my mother had to work, but she could not afford any of the child care options available to us.

We became "latchkey children." Malachi and I always came home right after school. Malachi always met me at home, and he went in first to check the closets and the basement for monsters and kidnappers. Together, Malachi and I did our homework and the chores that Mom laid out for us the night before. I am sure that, when Malachi thinks about that time, he remembers me as bossy. We bickered A LOT. (Imagine that! Siblings bickering?) We wanted to make sure that Mom would be in a good mood when she came home, and I knew that Malachi needed to be told to do things more than once in order to make sure that they got done.

When Malachi started experiencing new symptoms, I was starting high school, and I was given the opportunity to tune out. I got VERY involved in school activities and spent little time at home. My mother, exhausted by Malachi's constant needs and frustrated because she still did not know what was going on with him, just could no longer have him in the home. Malachi moved to my Dad's. For many years afterwards, I did not really know him or the



"A Sibling's Perspective"

person that he became. Maybe if my life with him had not been so intense when we were younger, I would have stayed connected with him during that time. My respite in high school was **WONDERFUL** for me, but it came too late in my relationship with Malachi. As I work to reestablish my relationship with him, I have a lot of regret. I can look back and say that respite would have been very important to us all at a crucial time in our lives.

So, in Malachi, I have a special sibling. I never had a brother who screened my dates or scared off my bullies or who my friends had crushes on when I was younger. When my parents divorced, I never talked to Malachi about my anger, and he will not celebrate my wedding day the way that I always felt a brother should. We might never have a deep meaningful conversation about our life paths. I will always miss all those things with him. But Malachi is one of the greatest teachers I ever had, and, these days, I am learning to enjoy all of the things we are able to do together and appreciate all of the things that he is. He is a very special sibling.

— *Anonymous, 1997, Sibling*

A Sibling Perspective

My brother David Eugene Ownby was born with multiple disabilities—profound mental retardation, epilepsy, cerebral palsy, and microcephaly. I was 3 years old when my parents brought him home from



"A Sibling's Perspective"

the hospital. They gave me a life-size doll that day -- but I wanted the real baby. I always took my responsibility of being the big sister seriously. I made sure that I "protected" David. When other kids made fun of him, they quickly got an education in disability awareness. I made sure they knew that David had feelings just like the rest of us. Although he could not talk, he still knew when someone was making fun of him. Little did I know I was becoming an advocate.

David required a significant level of care. Both my parents worked, and, while most any babysitter would watch me, few wanted to watch David. My parents tried many variations of baby-sitters, from live-in nannies to next-door neighbors. Most often sitters would watch me and David for a week or two and then David would have a grand mal seizure. That coupled with the rush to the emergency room would usually result in the sitter agreeing to watch only me and not David.

Respite was not an option for my family in the early seventies. While my family worked with many therapists and social workers, the only options given to them were permanent foster care or institutionalization for David. Neither sounded very appealing, but my parents' ability to function as a family was severely compromised by the time David was 5 years old. My parents needed a break from the demands of caring for David. They approached the social workers about institutionalization. A



"A Sibling's Perspective"

"state of the art" institution had just been built 8 miles from our home. This service was touted as the best option available. Even still, the waiting lists were long, and David was denied admission time and time again. My father knew Senator Hubert Humphrey and, with his political clout, my parents did what they thought was the best thing for David and my family -- institutionalized David.

While having David cared for on a daily basis by caregivers in the institution was a relief, my family quickly learned that institutional life was not conducive to normalization -- it was not a home. My mom quit her job at the Library of Congress to manage the institution's library and be close to David. I quickly became involved with Special Olympics and volunteered there most Saturdays. My family and I stayed actively involved in David's life, bringing him home on the weekends and visiting often during the week. While this seemed to work for our family, I always felt that David was cheated. I did not think it was fair that he had to live there. I vowed at age 7 to "grow up" and change things for people like my brother.

I had to wait until I was 18 years old to become employed at the institution where David lived, and, when I did, I got a job there. I wanted to know what went on behind closed doors. While my mom had some sense of institutional life, she was far removed from the living units and day-to-day activities. I was employed as a direct care aide. I quickly learned



"A Sibling's Perspective"

what I had always felt -- institutional life should not be an option for people like David. This environment was volatile, violent, uncaring, and stripped residents of their basic human dignity. As a young adult, I vowed to find David a better living situation. I wanted to become a disability rights advocate and work to change the system, allowing real choice for families and people with disabilities.

In seeking services for David, I faced what so many families still face -- closed doors, long waiting lists, and lack of services. The care David received at the institution was never good enough for me and had gotten considerably worse. More frequently, my parents and I met David at the emergency room with unexplained broken bones, bumps, and bruises.

In May 1992 David was left unattended in his institution bedroom after a series of grand mal seizures and aspirated. When institution aides found him, he was unconscious, with no respiration or pulse, and was cyanotic. He was rushed to the hospital and lived on life support for 2 months.

David had taught me long ago to never give up. He was certainly a fighter. He always bounced back from an injury or illness, and there were so many -- we all thought for sure he'd live through this too. While David struggled to live, this fight was too hard. In the time he had been left unconscious, he suffered significant brain damage. He was now blind, paralyzed, unable to swallow, and all the large



"Caregiver's Perspective"

organs in his body had begun to atrophy. My little brother was dying and my advocacy was too late.

David did die, but not in vain. While my efforts to help him move into a group home failed him, his death, my advocacy, and many others' resulted in 80 other residents having the real choice to live in a home. While I advocated to close this institution, after 5 years it remains open, but considerably smaller, better staffed, and closely watched by agencies providing oversight.

I learned from David to laugh, to have fun with the little things in life, and to persevere. I held David's hand as he lay dying and promised him I would work to ensure that no one else would have to suffer this way and that I would commit my life to making real choices for families and people with disabilities. I promised to share his story and make sure as many people as possible knew him. While David and I can no longer do McDonalds on a Saturday afternoon, and I'll never again have a big bear hug from him, he is alive in the work that I do. His life has given me my perspective.

— *Lisa Ownby, 1997, Sibling*

One Caregiver's Perspective

Respite caregiving for children with disabilities and their families truly presents an opportunity for a "give and take" relationship. This has been my experience from the time I decided to attend group



"Caregiver's Perspective"

training, through working as group caregiver, and finally when a family "match" occurred.

My initial interest in respite was both personal and professional in nature. Being a single person without children left me feeling the need for contact with children, and my work in the social/health care field made working with children with disabilities a natural. I truly felt that I had personal traits of an affinity for children, patience, and a desire to learn and help a family. At that point, I signed up for training without knowing the specifics. What an informative, supportive, friendly, and nonthreatening experience!

Following initial training, small group exposure to children and the opportunity to discuss the children's needs and personalities with their families gradually increased my confidence and my joy in understanding that children with disabilities appreciate interest, hugs, snacks, toys, walks, playing ball, swings and slides as well! Challenges are there too! They may come in the way of feeding, behavior challenges, toileting, or special wheelchair accommodations, which may initially be unfamiliar to caregivers.

This is where the "give and take" occurs on the part of caregivers and families. Caregivers need training, feedback, and encouragement from the family "experts" in order to best understand the child's limits and special needs. Caregivers may appear to ask many questions, seem anxious, and



"Caregiver's Perspective"

anticipate what to do in an emergency. I believe families can aid caregivers by remembering their own initial thoughts and feelings about helping their child with his/her limitations. On the other hand, caregivers may want to appear knowledgeable and confident and not ask too many questions! Families, please anticipate this and **VOLUNTEER INFORMATION!**

My caregiving experience with a 9 year old and his 6-year-old brother has truly been rewarding and fun! This match occurred following group respite in which I had the chance to interact, observe, and build a relationship with both brothers and parents. A need for individual respite was there, and I had the time and geographic availability. Truly a match made in heaven! I really feel that this family provided information, training, and demonstration about their son's needs. I had the opportunity to question, observe, and build a relationship with the parents as well. I believe that caregivers need to maintain contact periodically in between respite dates to develop rapport. This also helps families feel freer to call upon the caregiver, particularly families that typically "do it all" or have difficulty in asking for help. Families and caregivers need to communicate and appreciate the gifts each has to bring to this partnership. The Partners Plus program is truly partners in action!

— *Linda Malone, 1997, Caregiver*



Stress, Special Challenges

Stress

The potential for stress exists in all of our lives. Stress may be good or positive stress (eustress), or bad or negative (distress). The key to coping with stress depends on how you perceive a situation or life event. Stress is also closely related to your view of how hard or easy it may be to manage the event. For example, going on vacation can be perceived as both good and not so good. Many of us welcome vacations! Yet, vacations may be a major source of stress if you consider the packing, the drive, making reservations, or scheduling time to be difficult. Many strategies are available to both families and caregivers to help cope with daily stress. Included in the following pages are things families and caregivers can do to reduce stress, prevent *burn out*, and ensure successful respite relationships.

The Special Challenges of Parenting

Being a parent involves many changes, which may be perceived as stressful. Families who have children with special needs share the stresses of all families facing the challenges of parenting. In addition, they may have other challenges related to their children's special health, education, and care needs. Many resources are available to help families cope with these special challenges.



Learning to Cope

The Special Challenges of Caregiving

Being a caregiver for children with special needs can be stressful too. Caregivers are responsible for the children in their care. If those children need extra attention or medical care, caregivers are more challenged. In addition, it takes time to become comfortable with children and familiar with their needs and strengths. Not knowing what to expect from children can be stressful. Caregivers who are still learning about the children in their care may experience stress.

Coping with Stress

If you perceive a situation as stressful or hard to manage, you can reduce your stress by using a variety of coping strategies. Consider some ways you deal with stressful situations or special challenges. You might already know strategies that work well for you. For example, it might help to talk with family and friends in hard times.

Families often use respite to cope with stress. Taking a break from daily demands not only is relaxing, it allows families time to try the strategies listed on the following page. Families may want to talk with caregivers about how they use respite time to cope with stress.

Caregivers may need specific ways to cope with the challenges of working with children with special needs. Caregivers and families need to take time to talk after respite takes place. Was there anything that was stressful? Is there more information families can share? Are there



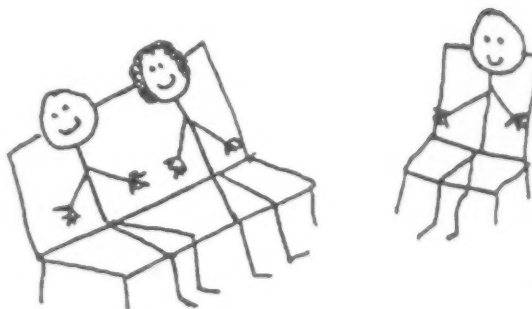
Dealing with Stress

new skills the caregiver can learn? Certain caregivers may want soothing music playing as they work with your child(ren) or use other methods to create a calm atmosphere. Families can encourage caregivers to talk about how they handle stress. Together, caregivers and families can work out ways for caregivers to relieve stress during respite. The following fact sheet lists strategies you may find useful in reducing your stress.

Strategies for Dealing with Stress

People deal with stress in many ways. Here are some examples:

- Seeking information
- Sharing information
- Learning new skills
- Doing something that makes them laugh
- Listening to something they find soothing
- Planning ahead
- Finding a favorite cartoon that brings a smile to their face
- Walking, jogging, hiking, swimming, playing
- Communicating openly
- Taking a break



Challenges of Respite

The Challenges of Respite

Building effective partnerships takes time and skill. Families and caregivers need to know how to work together for successful respite care.

One problem families often face is keeping caregivers. Families tell us many respite caregivers cancel appointments. We also know that many caregivers stop providing respite. Respite caregivers cancel or quit for many reasons. Why do you think they quit? The information in this section will help you understand why and help you develop strategies to build successful respite partnerships.

Caregivers may stop giving respite for the following reasons:

- **Respite is harder than they expect.**
- **Time demands are too great.**
- **Physical demands are too great.**
- ***Burnout* occurs.**
- **Training was not adequate.**
- **Patience wears out.**
- **They don't feel appreciated.**
- **They are not paid enough.**



Meeting the Challenge

Meeting the Challenge

Taking these steps can help you meet the challenge of respite:

- Help caregivers to know your family.
- Help caregivers to know your child.
- Communicate your purpose for respite.
- Develop and carry through with a thorough training plan.
- Avoid overuse of a caregiver.
- Show your caregiver respect.
- Show your caregiver appreciation.
- Be clear about your caregiver's terms for providing care.
- Be considerate with schedules.

Little Things Can Make a Difference

It is important to recognize and appreciate your caregivers. Here are some ways you can show them what their caregiving means to your family.

- Send notes or tell your respite caregivers what a difference they are making in your family's life.
- Tell them how well they are doing a specific task.
- Tell them how you appreciate the extra effort they make.
- Remember your caregiver on special days.



It's the Little Things

- Send or give them pictures made by your child.
- Do things for your caregivers that would be meaningful to them.
- Write about your caregiver and put the article in a newspaper or newsletter.

Successful Family and Caregiver Partnerships

Many components are helpful in establishing and maintaining successful partnerships. Families and caregivers should strive to accomplish these goals:

- Appreciate differences in skills and approach.
- Be willing to learn from each other.
- Ask each other for help.
- Allow time to talk with each other.
- Share experiences.
- Be willing to work together, even when differences occur.
- Be flexible in trying new ways.
- Have a sense of humor and fun.
- Be patient when things are not clear or exact.
- Share commitment to children with special needs.



Notes on this Section



4

Section 4

All Kids Like Cookies
activity

All Kids Like Cookies

All Kids Like Cookies

Children with special needs are important members of respite partnerships. The following activity is designed to allow you the opportunity to experience some of the daily challenges children with special needs face. This may be useful in understanding a child's perspective and keeping that in mind when developing respite partnerships.



We know children with special needs are more similar to other children than different. "All Kids Like Cookies" is a series of activities designed to help persons without special needs experience challenges children with special needs face every day. You can do the activities on the next pages by yourself or with a group. Answer the questions at the end of each page as you finish each activity. This will help you become more aware of what it is like to have special needs. As you will see, from the perspective of the child with special needs, the world is a more challenging place.

We cannot help until we understand.

We cannot understand until we feel.

We cannot feel until we become.

(Council for Exceptional Children)

Adapted from:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D.
(1993). *SpecialCare curriculum and trainer's manual*.
Lightfoot, VA: Child Development Resources.



Activity Sheet

All Kids Like Cookies Activity Sheet

The following activities can be done alone or with a group. During the activities you remain yourself, but a special challenge is added. Think about how you feel when doing each of these activities and be aware of any adaptation you make.

To experience a visual impairment, you will need:

- a blindfold
- a pitcher of water
- an empty glass
- a crayon or other marker
- a page out of a coloring book or a crossword puzzle
- a child's storybook or magazine

- Put a strip of cloth over your eyes and tie it around your head to make a blindfold.
- Pour water from the pitcher into the glass.
- Color the coloring book page or complete the crossword puzzle.
- Read the storybook or magazine.

Questions

- How did you hold your head while pouring water, coloring, and reading?
- If doing this activity with a group, did anyone talk you through the tasks?



Activity Sheet

- What other senses did you use to help yourself? (touch, sound, smell)
- Did it matter that you were coloring out of the lines or what color you were using?
- Were you able to complete the crossword puzzle?

Vision helps a child learn about the objects and people in the world around them. Few children are totally blind. A child is considered to have a visual impairment if the child's ability to see after correction limits his ability to learn through vision.



To experience a speech and language impairment, you will need:

a bag of large marshmallows and gauze
one other person or a small group

- Put enough marshmallows or gauze in your mouth to fill it; two or three usually work.
- Say your name and give your address or phone number.
- Ask your partner or others in the group to bring you something.
- Tell your partner or others something you did today.



Activity Sheet

Questions

- How were your words spoken differently?
- How did you feel when others did not understand you?
- If you spoke this way all the time and others laughed at you, would you want to talk very much?

Sometimes children with speech and language impairments stop talking rather than cope with the difficulty of getting people to understand them.

To experience a physical disability that affects using the smaller muscles in your body, like the ones in your fingers, you will need:

a pair of large garden or work gloves
a puzzle
a string and macaroni with holes or beads
very small toys that have moveable parts

- Put the gloves on.
- String the macaroni or beads.
- Put the puzzle together.
- Play with the toy.
- If you are wearing a watch, take it off and put it back on.
- If you are wearing earrings, take them out and put them back in.



Activity Sheet

Questions

- Were you able to pick things up easily?
- Did you need more time to put the puzzle together?
- Were you able to put on your watch and/or earrings?

To experience a physical impairment that affects the large muscles of the body (like the ones you use for walking) you will need:

a kick ball

a large toy like a stuffed animal or truck

a video

- Place the ball between your ankles and keep your hands folded together.
- Walk 10 feet with the ball between your ankles and pick up the toy or video.
- If doing this with a group, hand the toy or video to someone else.

Questions

- Did you take a long time to get to the toy or video?
- Did you feel awkward?
- Did you drop anything?



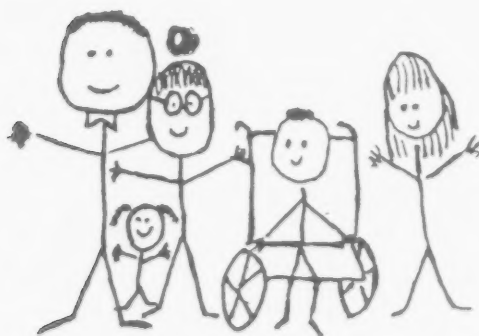
Activity Sheet

Children first learn to explore their surroundings by using their large muscles to move around. Children learn how things work by using the small muscles of their hands to explore toys.

Children delayed in their motor development have difficulty learning to become physically independent because they cannot move well. Children with small muscle development delays may have difficulty feeding and dressing themselves or learning how things work because they cannot use their hands and fingers well.

Source:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *SpecialCare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.



Notes on this Section



5

Section 5

finding respite

caregivers

Finding Respite Caregivers

Preparation

Finding a good caregiver is often difficult. Many people decide to go out for dinner, take a quiet walk, run errands, or attend a sports activity, then consider their choices and plan for child care. But what if you have no plan?

Planning ahead and putting in the time and effort to train individuals to care for your child's specific needs will give you regular respite. Over time, you will come to trust and rely on your caregiver's help. On the other hand, if you wait until an emergency or crisis develops, you will feel helpless, isolated, and overwhelmed.

For Example:

Miguela and Tony want to go shopping for the evening. They would like to go without their daughter Angela, who has cerebral palsy. They cannot simply call the 20-year-old college student, Pat, who lives next door because a caregiver needs special training in helping Angela move and feed herself. **Or can they?**

Yes, Miguela and Tony can call Pat to provide child care, if they plan ahead.

In developing their plan for respite, Miguela and Tony need to recruit several people, including Pat, who are interested in providing care for Angela. Then they need to provide training to these caregivers. The advantage of having several trained caregivers is that caregivers feel more comfortable saying no when they need to, knowing that a family has someone else to call.



In-Home Respite Care

When you have a child with special needs, it is important to develop a plan so that you can have time away from the demands of parenting. Partners Plus can help you develop a plan for recruiting and training respite caregivers.

Before looking for caregivers, think about the type of respite your family wants. Families have many choices for what respite will be like. Evenings might be the best time for you to get respite, or perhaps a morning out. Maybe you and your family need to spend a weekend away. Your family might want a combination of all three.

You might want respite in your home, or you may prefer to find someone to care for your child out of your home. You may want to enroll your child in a before- or after-school or recreation program in your community. You may want to build a respite cooperative with other families who have children with special needs. In a cooperative, families trade care.

The benefits and disadvantages of in- and out-of-home care and of cooperatives are listed on the next few pages.

In-Home Respite Care

Advantages

- You do not have to arrange transportation for your child or for any special equipment needed.
- Your child does not have to adjust to a new environment.
- Other children in your family can also be cared for at the same time.



Out-of-Home Respite

Disadvantages

- Having a respite care provider in your home can feel like a loss of privacy.
- You may have to arrange transportation for your respite care providers.
- Some respite care providers may already care for other children in their homes but may not be available to come to yours.

Adapted from:

Author. (n.d.). *Respite care: A guide for parents*. Chapel Hill, NC: Collaborative Research Systems, Inc., and Association for the Care of Children's Health, p. 3.

Out-of-Home Respite Care

Advantages

- Your child may have an opportunity to interact with other children and adults.
- When your child is in out-of-home respite, other family members can take a break but still be at home.
- Your child has an opportunity to be included in community programs.

Disadvantages

- Out-of-home respite may feel very different from usual baby-sitting.
- It may be hard to leave a child in an unfamiliar setting.
- Children may have a difficult time adjusting to a new place.
- You may have to provide transportation.
- Medication and special equipment have to be packed and taken along.

Adapted from:

Author. (n.d.). *Respite care: A guide for parents*. Chapel Hill, NC: Collaborative Research Systems, Inc., and Association for the Care of Children's Health, p. 3.



Family Cooperative Respite

Family Cooperative Respite Care

Advantages

- Families provide respite care for each other instead of paying out of pocket.
- Parents may be more comfortable leaving their child with a person who is experienced in caring for a person with special needs.
- Cooperatives build support networks for families.

Disadvantages

- It may be an additional demand on parents.
- It may be difficult to work around family schedules.

Finding Respite Caregivers: Circles of Family and Friends

One way to help you think about your respite care recruiting plan is to consider your natural support network. You might call this network your circles of family, friends, and community programs. Consider yourself at the center of this network. Surrounding you are people from various groups. These groups interact with your family in some way to provide different levels of support. Think about your circles of support and the people in these circles.

For example, one circle is the people in your neighborhood. Who are your next-door neighbors? Who lives down the street? Do your neighbors know anyone who might be



Circles of Family and Friends

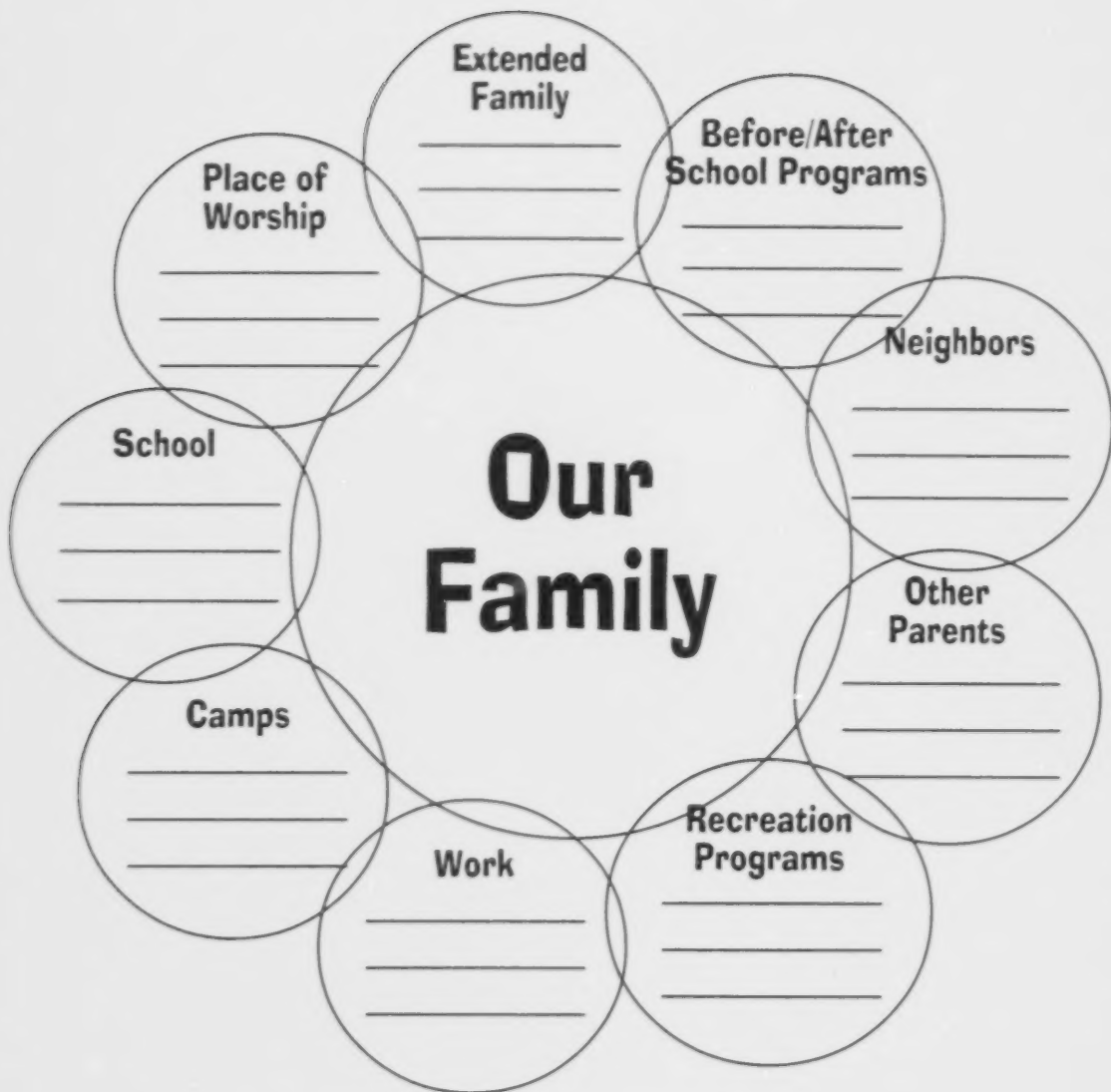
interested? What about the circles of support in your church or synagogue? Your child's school? Your place of work? Are there extended family members who would be more likely to provide child care if they were adequately trained? What community programs are available?

Another way to find people from your circles of family and friends is to invite several parents of children with special needs to your home to share ideas about what worked for them. Begin by drawing the circles and labeling them. Then, think of people you might ask. You may also consider asking your service coordinator, case manager, or child's teacher to help you in this activity.

By identifying even one person from each circle, you have started a list of possible respite caregivers. Now, find some time to talk with them about Partners Plus and ask them if they would be interested in learning more.



Circles of Family and Friends



Finding Respite Caregivers

Other Ways to Find Respite Caregivers

Partners Plus helps families think about groups of different people who may be interested in providing respite care. Recruiting other parents to start a cooperative may also become a part of your plan. As mentioned earlier, cooperatives offer families another option for child care.

As you move beyond your circle of friends, neighbors, family, and community programs, consider other people in your community (e.g., workers from community agencies, local universities, or child care centers). Community agencies may maintain a list of people interested in providing child care or know of organizations or programs that do. A list of community groups that may be able to help you find a respite caregiver follows.

Resources in Your Community

The following organizations in your community may help you get in touch with caregivers:

- Child care resource and referral agencies
- Home child care providers
- Child care centers
- Schools
- Mental health/mental retardation agencies
- Home health agencies
- Hospitals
- Civic or community groups
- Senior centers



Choosing Potential Caregivers

- Recreation programs
- Faith groups
- Universities/colleges - students (may need volunteer hours or work experience to meet graduation requirements)
- Volunteer organizations
- Before / after school programs
- Camps

Choosing Potential Caregivers

In the Partners model, families and caregivers choose each other for a respite care partnership. This takes place by a natural selection in much the same way as we choose our doctors, dentists, preschools, neighborhoods, places of worship, and friends. In making these selections, we are looking for a good match with our own values, beliefs, and ways of doing things. Families often make their choices based on special qualities they want in an individual respite caregiver, or a community program that offers respite through group care, such as before and after school programs, camps, or recreational activities.



Partners Plus offers opportunities for families to choose potential caregivers. In group training, families and caregivers meet, talk, and listen to each other. Partners Plus can help families and caregivers get together through social events such as potluck dinners or picnics, giving families a chance to see how their children and potential caregivers interact together.



Notes on this Section



6

Section 6

interviewing

caregivers

Interviewing Potential Caregivers

caregivers meet, talk, and listen to each other. Partners Plus can help families and caregivers get together through social events such as potluck dinners or picnics, giving families a chance to see how their children and potential caregivers interact together.

For communities that choose to maintain a caregiver directory, each Partners Plus caregiver fills out a caregiver profile. These communities would designate a place to keep each profile on file for families. Communities may also maintain a list of programs where respite can take place.

The profile is much like a resume or job application. It gives a family information they can use in deciding if they want to get to know a caregiver better through an interview. An interview is a chance for both family and caregiver to ask questions and learn what each expects from the other.

A sample caregiver profile is included in Section 8. Families can duplicate this and ask caregivers to complete prior to an interview as part of the interview process.

Interviewing Potential Caregivers and Caregiving Programs

Interviewing is an important step in choosing a caregiver or caregiving program. Take some time to think about your respite schedule and respite needs before you begin to interview caregivers or community programs.



Interviewing Potential Caregivers

Many families have told us that selecting a good caregiver or child care program is sometimes hard for them to do. We have included some simple tips on interviewing to help you make a good match for your family.

1. Be prepared.

One key to a more relaxed interview is to be prepared. Prepare yourself by reviewing the caregiver profile or program description. Questions on this form ask the potential caregiver or program director to provide information on education or training in child development or child health, first aid, CPR, or other certifications they may hold. Potential caregivers and programs are also asked to describe why they are interested in providing respite care or including children with special needs into their program.

Make notes as you review the caregiver profile or program description. What else would you like to know about the person or program? Do you want to know more about a caregiver's or program staff's education and training? Do you want to learn more about their experiences in working with children? You might also want to ask when a caregiver or program would be available to provide respite.

2. Decide how to conduct the interview.

Some parents are more comfortable doing a telephone interview first to screen potential caregivers or programs. If, after the initial contact, you decide you want to consider a person or program to provide care, you can schedule a meeting time for a



Interviewing Potential Caregivers

face-to-face interview. You might also consider whether you would like to have your child present at the interview.

3. Break the ice.

A good way to begin the interview is to ask potential caregivers or program directors about their interests and experiences. For example:

I see from your caregiver profile that you are interested in respite because . . . or,

I see from your caregiver profile that you already have some experience caring for children with special needs. Tell me what that was like for you.

If you are interviewing a program director, you will want to know more about the knowledge and skills of existing staff in including children with special needs. You may want to ask how new staff are trained to help children with special needs participate in all activities.

You will also want to ask questions about the program's accessibility as it relates to the individual needs of your child.

4. Ask open-ended questions.

Another good way to gain more information is to ask open-ended questions. For example, if you ask a person *Do you believe in punishing a child?*, you are asking for a response of yes or no. But, if you ask *How do you handle difficult behavior?*, the person can give you much more information on their feelings and specific examples. Some sample interview questions are included on the following pages.

Sample Interview Questions

5. Take notes.

As a potential caregiver or program director begins to share information, jot down some notes. Taking notes will help you to ask follow-up questions. It will be helpful to review your notes when you consider potential caregivers or programs later. You might decide ahead of time that your spouse or partner will take notes while you ask questions or vice versa. You may want to tape the interview instead. With a tape, you can listen to the caregiver's answers more than once. If you choose to tape, ask the potential caregiver for permission to tape-record the interview.

Sample Interview Questions

You may wish to ask several of the following questions when you interview potential caregivers. Adapt these questions when interviewing a community program director.

- **Tell us about your education and/or experience in working with children.**
- **Discuss your experience working with children with disabilities.**
- **Why are you interested in providing respite care services?**
- **Describe your strengths. How would you describe yourself?**
- **Why are you the right person for the job?**



Sample Interview Questions

- What are your thoughts about families who have children with disabilities?
- What would you do if we disagreed about something?
- If my child had to be taken to the hospital for an emergency, what steps would you take?
- How do you believe children's difficult behaviors should be managed?
- What would you do if a child deliberately hit another child?
- What would you do if you found a child with an open bottle you suspect is poison?
- Are you willing to take my child out on activities?
- Describe a difficult problem you've had to handle with a child. How did you handle it?
- Tell me about any special training or experience you might have.
- How would you know if my child likes a particular food or activity if he cannot speak?
- Are you willing to have a criminal background check done?
- Do you have CPR, first aid, and/or medication administration training?
- Do you have a valid driver's license?



Answering Caregivers Questions

Some Additional Questions To Ask Directors of Community Programs

- How do you encourage children to play together?
- How do you teach children to ask other children to play with them, share toys, take turns, express affection, and help other children?
- How do you help children to control aggressive behaviors?
- What kinds of small groups activities do you have that require cooperation and sharing?
- What agency or organization provides oversight or certification for this program?
- Do all staff working in the program have criminal history background checks?

Adapted from:

Osborne, S., Kniest, B., Garland, C. Moore, P., and Usry, D.
(1993). *Specialcare curriculum and trainer's manual*.
Lightfoot, VA: Child Development Resources.

Questions Caregivers Ask

Caregivers may ask these questions about what will be expected of them. Families should be prepared to answer them during interviews.

- Will I be expected to care for siblings as well?
- Will the parent be at home or away while I am providing care?



What To Do After the Interview

- If I receive a fee for my caregiver service, how will I be paid?
- How much will I be paid?
- What kind of training will I receive?
- How often will respite be needed?

Program directors often request families fill out an application that provides them with the kind of information they need for all children. There may be additional questions they ask that are specific to the needs of your child.

After the Interview

1. Reference checks

It is a good idea to check the references of a potential caregiver. The caregiver profile asks potential caregivers to provide the names of two people. You may choose to ask for more references. A *Reference Check* form is included in this manual as a guide to help you know what questions to ask.

2. Criminal record checks

To obtain a criminal record check on a potential caregiver, you can contact your state police. There may be a charge for the service. Criminal record checks are limited in the information they provide.



Other Factors To Consider

3. Follow-up

Be sure to thank potential caregivers for their time and explain how and when you will decide. You might say,

- We have decided to interview three people and do reference checks for each.
- We hope to have a decision in one week and will let each person know of our decision by phone or by a note in the mail.

4. How to Say No

Sometimes it is difficult to say no to a person. If you decide a potential caregiver is not the best person, be honest and direct. You might say,

- I was fortunate to have interviewed several qualified caregivers such as yourself and we have selected another person that we think best meets our needs.
- Thank you for your time and interest, but I don't think this would be the best match for us.

You may feel more comfortable telling a caregiver in a note, rather than over the phone.

Additional Things to Consider

Most people who want to care for children are responsible and love this work. Others may not be good choices to work with children. **Trust your instincts!** If you are uncomfortable



Other Questions To Ask

with a caregiver, he or she is not the right caregiver for your child. Please use the following to help guide you in selecting a caregiver. There are a few things to look for when talking to caregivers that might alert you to some concerns. Adapt the following questions for appropriate use for community program staff.

A Few Questions to Ask

- **Why do you want to care for my child? What do you hope to gain from this?**

Many people will answer that they love children. Some will say that they want experience working with children with special needs. Others will tell you that respite was important for their families. Some people want to make a difference in their communities by providing respite.

These are all the right words to use. Be sure to watch body language closely. Listen for answers that make you uneasy.

- **How do you deal with stress/anger?**

(Give the caregiver an example. What can be stressful about caring for your child? For example, does your child show anger by hitting? Ask the caregiver how they would deal with that stress.)

There is some stress involved in any child care setting. There are many different ways to handle stress, some positive, some not. Be sure you are comfortable with the answers you get.



Other Questions To Ask

- **Tell me about any lessons you learned from the way that you were raised that influence the way you interact with children.**

Often, people care for children the same way that they were raised. You may want to ask other questions that get the same information: Tell me a little about yourself. What is the thing that you remember most about your childhood? Sometimes, people can work through bad experiences as children to become loving, capable caregivers. If you have concerns about something a caregiver tells you about his or her childhood, ask about how it affects the ways they might take care of your child. Again, be sure to watch their body language.

- **Will you be taking any medicine that will affect your ability to care for my child? Do you have any physical limitations that might affect your ability to take care of my child?**

These questions might give you some information about the medical and emotional history of a caregiver. Feel free to ask a caregiver who will be taking medicine what those medications are and how they will affect him or her. Find out if there are any side effects to the medicines and what they are. Also, talk about where medicines will be kept so that the child cannot get to them. Remember, a medical history might not mean that a caregiver is unsuitable.

- **Tell me about how you discipline your children. How would you discipline my child if he were not behaving?**



Noticing Warning Signs

Watch for answers that do not agree with the way that you want your child to be disciplined, especially anything that involves physical contact. This might be a good time to talk with a caregiver about how and when you discipline your child.

- **How long have you lived in Virginia?**

Remember, criminal history checks only give information about convictions in this state. If a person has moved around a lot, ask why. Again, watch body language!

Some More Things to be Alert to When Interviewing and Screening

- **Unusual interest in your child's medication(s)**

Remember, a person may need to know a lot about the medication a child takes. We encourage caregivers to ask as many questions as they need to make them comfortable in working with children. If a caregiver's questions do not seem to relate to understanding your child, you may have some concerns.

- **Curiosity about where liquor or firearms are kept in the house**

Again, a caregiver may be asking these questions because they want to keep your child safe. However, if caregivers want to know where the keys to the liquor/gun cabinets are kept, you may need to ask why they need that information.

Visit the Caregiver's Home

- References cannot give positive information about a caregiver
- Caregiver wants to care for a child only of a specific age or gender

If a caregiver states such a preference, ask why. Watch body language!

- Caregiver does not want you to visit while she is providing care

Suggest to a caregiver that you might drop by while she is providing care. If a caregiver is not comfortable with your dropping by, find out why. Remember that caregivers must plan for their own lives. They will need to know when you plan to be back so they can plan the rest of their day.

Things to Look for When Visiting a Caregiver's Home

- A lot of video equipment/cameras
- Books or pictures of children that make you uncomfortable
- Medicine, alcohol, or drugs out in the open
- Weapons not stored safely in the home
- Room arranged in a way that does not allow children to play freely



Visit the Community Program

Look at the space where your child will spend time in respite. Make sure that the environment is safe and comfortable for your child.

Is there room for your child and your child's equipment? Are there a lot of sharp corners in the room? Can your child play in this room? Are there fragile decorations that your child might bump into? How will the caregiver protect items so your child will not break her things? Will your child be kept in a small room or have freedom to move from room to room?

Things to Look for When Visiting the Community Program

- Too much attention from adults that may interfere with the children's interactions
- Are children with disabilities situated next to children without disabilities so they may interact easily
- Do all children get to lead activities and be successful in front of each other
- Are the equipment and play materials safe and in good working order
- Are the toys and supplies appropriate for the age group and their abilities
- Are the number of toys available limited intentionally, in order to encourage children to share and engage in the same activity

Adapted from:

Osborne, S., Kniest, B.,
Garland, C. Moore, D., and
Usry, D. (1993).
*Specialcare curriculum
and trainer's manual.*
Lightfoot, VA: Child
Development Resources.



Watch Your Child for Signs

Things to Look for After Care Has Started

There are few signs to watch for in your child after care has started that may be signs that he is poorly treated in respite.

- Eating a lot less or a lot more
- Sleeping a lot less or a lot more
- Unusual fear of adults

Children from around 5 months to a year typically go through a period of *stranger anxiety*. At this time, children are learning to separate people they know well from those they do not. At this stage, it may take time for children to adjust to new caregivers.

- Sexually acting out with younger children or toys
- Increased violence or anger
- Rashes and bruises that are not explained
- Unexplained stained and/or torn clothes or underwear

A Few Final Words

It is very important that you feel comfortable with your caregiver. If the answer to any question makes you uneasy (even if it is the answer to only one question), then that



Evaluating Your Respite Decision

person is probably not the right caregiver for your child. Your instincts might give you the strongest clue about how well a caregiver will work for you and your family. Trust yourself.

Summary

Now that you have finished recruiting, screening, and interviewing, you are ready to select your caregiver.

Consider these questions about caregiver(s) you have selected:

- Will she feel comfortable caring for your child with special needs?
- Will she be willing to spend time learning how to care for your child?
- Will she be willing to learn about your family?
- Will she be warm, affectionate, and enjoy children?
- Will she have respect for your beliefs and values?
- Does she have good character references?



7

Section 7

developing your
personalized
training plan

Developing a Training Plan

Developing a Personalized Training Plan

The Partners model is based on the belief that families know how to care for their own children and that they have the skill and knowledge needed to train their own respite caregivers. The family and caregiver together decide the specific amount of personalized training needed to care for a child. Training time will vary according to child, family, and caregiver needs.

Remember, caregivers learn in many ways. The **Caregiver Manual** asks caregivers to think about how they learn best. Before you begin training, talk with your caregivers about how they think they will learn your child's routine best. Work with your caregivers to develop a training plan that blends your teaching style and their learning styles.

Some caregivers may not be sure about how they learn best and may want you to go ahead with your training plan. During this process, caregivers may find certain training techniques that work best for them. It is important to be ready to change your training plan to meet everyone's needs.

There are four simple steps to help a family develop a personalized training plan. This training plan is helpful for all caregivers, those providing individual and group care, in families homes or community programs.

These steps are explained on the following pages.



Step by Step

Step by Step: A Guide to Developing Your Personalized Training Plan

To develop your training plan, follow this step-by-step guide. The worksheets and examples in this section will help keep you organized. Clean copies of all worksheets are included in Section 8.

Step 1: Identify training goals.

What should your caregiver learn about your child and family routines?

Step 2: List training methods.

What teaching methods will you use?

Step 3: Use resources to help train caregivers.

What information will you use to help your caregiver learn?

Step 4: Evaluation

How will you and your caregiver know when your caregiver has learned a specific skill or routine?



Identify Training Goals

Step 1: Identify training goals.

Partners Plus is based on the belief that families can train their own respite caregivers using their child's daily routines. First consider what part of the day you want respite. If you think you will schedule respite in the morning, then the morning breakfast routine would be helpful to use as a basis for training. If you think you are more likely to schedule respite in the evening, then dinner and bedtime routines should be considered in developing your training.

Your training goals will be based on the daily routine that you selected for training. Goals are broad statements of what you want to achieve or do. For example, you decide that you most likely would have respite care take place during lunchtime between noon and 1:15 p.m. Your goal, therefore, may be for your caregiver to be able to feed your child lunch.

If your child will be participating in a community program, you will need a clear understanding of the schedule of activities for children enrolled in the program. You and the staff will need to communicate well in developing a plan for training program caregivers to include your child in the daily routines.

The number of training goals each family has will vary and will be determined by the needs of the child, his or her routine, and the length and time of day involved.

What do you want your caregiver to learn about your child and family routines?



List Training Methods

I want my caregiver to learn about these routines:

Goal 1: (Example) My caregiver will be able to feed
Maria lunch.

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____

Step 2: List training methods.

At this point you should have at least one training goal. Now it is time to consider how you will train your caregiver.

One family tells us that they train their respite caregiver by modeling and shadowing. The family asks a caregiver to spend several hours with them during a period of the day such as lunchtime. This is a time when many routines can be observed. This gives the caregiver the opportunity to watch



List Training Methods

how the parent interacts with the child during these routines. We call this *modeling* the ways you want someone to care for your child. By spending several hours with the family, the caregiver can also watch play activities and a nap routine. On the next visit the caregiver helps the parent, or *shadows*, in the caregiving routines. This gives the caregiver another learning experience.

Another family tells us that they train their respite caregivers by making a videotape of their child's daily routines. This gives the parent the opportunity to select specific routines to tape for training. It also gives the caregiver the opportunity to view the videotape, write questions, view the routines with the parent, and discuss.

It is important to think about all the different ways you might teach your respite caregivers so they can learn how to provide quality care for your child. Will you have the caregiver learn to feed your child by watching you? Will you want the caregiver to assist in feeding your child? You may also want to ask the caregiver questions about his or her skills and comfort level in feeding your child. There are many ways to train and you have many options available to you. Some suggestions include the following:

- **Modeling** (showing)
- **Videotaping** (another way of showing)
- **Shadowing** (helping)
- **Talking, telling, describing**
- **Writing** (another way to tell or describe)



List Training Methods

- Answering caregiver questions
- Sharing ideas

Even if you choose other ways of training, it is a good idea to have important information and instructions in writing, in case your caregiver needs help remembering what you have discussed.

What methods will you use to teach your caregivers?

In order to reach these goals I will use the following methods:

Goal 1: **My caregiver will be able to feed Maria.**

Methods:

1. **(Example) My caregiver will watch me feed Maria at lunchtime.**

2. _____

3. _____



Use Training Resources

Goal 2: _____

Methods: _____

1. _____

2. _____

3. _____

Step 3: Use resources to help train your caregiver.

It may be helpful to gather resources you can use when training your caregiver. There are many, many information resources available to us. You also may want to network or get in touch with others, so you will have links to new information.



Locating Training Resources

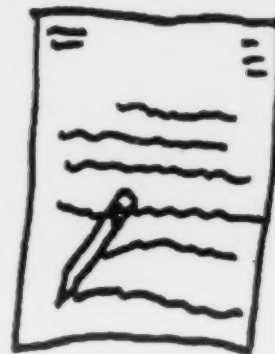
You may want to give a caregiver written information about your child's diagnosis, other special health care needs, medications, or sibling issues as a part of your training.

Will you tape a home video of a lunchtime routine? Would you like to give your caregiver any handouts on special feeding issues similar to your child's? Do you have information that you want to share on special feeding techniques from your child's occupational therapist?

The following is a list of organizations and services that you may want to contact for resources that you can use in training.

Where to Find Resources:

- Local early intervention programs
- Doctors, nurses, therapists, social workers, and teachers
- Local, college, and university libraries
- Parent Resource Centers
- Parent to Parent Networks
- Local hospitals
- Parent Training Information Centers
- National Information Center for Children and Youth with Disabilities (NICHCY), call toll-free 1 (800) 695-0285
- *Exceptional Parent: Parenting Your Child or Young Adult with a Disability* (magazine)
- National Health Information Center, call toll-free 1 (800) 336-4797
- Internet (accessible through many "on-line" services)



Locating Training Resources

What information will you use to help your caregiver learn?

These are the resources I would like to use:

- Books
- Handouts
- Videotapes
- Audiotapes
- Computer search
- Resources I develop
- Other (please describe)

Step 4: Evaluation

You now have some goals, have planned how you will teach a caregiver, and have some resources to help you in your training. But how do you know if your training plan works? The final step in developing your training plan is evaluation.

Evaluation helps you to know how well your training goals have been met. Through evaluation you can tell how well you presented the training, what your caregivers learned, and if they can do the skills or tasks identified in your training plan.

You can evaluate in several ways. One way is to ask your caregiver to answer some questions in writing or in a discussion. You may also ask your caregiver to show you a caregiving routine or skill you have taught.



Evaluate the Training Plan

Just as it is important to include caregivers in the development of the personalized training plan, it's also important to seek and include their ideas in evaluation. Families will have some ideas for deciding when their caregivers have mastered skills that will allow them to provide respite care. But caregivers may also have some ideas about how they can show that they are ready to care for the child(ren) without supervision.

How will you and your caregiver know when a specific skill or routine has been learned?

I will know a specific skill or routine has been learned when we accomplish the following:

Goal 1: (Example) My caregiver successfully feeds Maria with no assistance.

Goal 2: _____

(Goal 3: _____



Sample Personalized Training Plan

Sample Personalized Training Plan

Child's Name: Maria

Date: May 10, 1997

Routine: Lunchtime

Time of Day: Noon - 1:15 p.m.

Step 1: Training Goal

My caregiver will be able to feed Maria lunch.

Step 2: Training Methods

My caregiver will watch me feed Maria at lunchtime.

My caregiver will assist in feeding Maria.

My caregiver will feed Maria with some assistance.

I will watch my caregiver feed Maria.

Step 3: Resources

I can give my caregiver

- a handout on feeding techniques developed by Maria's occupational therapist.
- a handout on special feeding problems in children with cerebral palsy.
- a video of lunchtime routine taped by us at home.

Step 4: Evaluation

I will ask my caregiver questions about skills and comfort in feeding Maria.

I will watch my caregiver feed Maria two bites.

I will watch my caregiver prepare and feed lunch to Maria.



Training Tips

Training Tips

- **Be clear with your instructions.**

Make sure your caregiver understands what you have said. For example, if your child's care involves medical equipment such as an apnea monitor, be sure to describe what the equipment does and how it is used.

- **Be very specific.**

Instead of telling your caregiver(s) to feed Kim, tell your caregiver to feed Kim using the purple plastic spoon. Then show the spoon to your caregiver and where it is kept.

- **Use your knowledge and resources to train.**

Think about how you learned from others. Think about how the professionals you work with showed you how to position or feed your child or to handle different behaviors. Then adapt these methods to your style of teaching.

- **Give your caregiver written information.**

Providing written information is another way to help caregivers learn. Share articles, diagrams, or books with your caregiver. Visit the parent resource centers in your public school district to discover new resources. Give important instructions or information in writing even if you have shared it in other ways.



Training Tips

- **Talk to your caregivers about the information you give them.**

Your caregivers may have lots of questions about words or unfamiliar terms that you use. Check to see if your caregiver has the same understanding as you do about your child with special needs, etc.

- **Use diagrams or pictures.**

These are often helpful to show caregivers how to use sign language or to play with your child.

- **Be sure to get your caregiver's opinion.**

If your caregiver did not benefit from a certain type of information, you will know to try something different.

- **Write down important facts or information.**

Use the forms in your manual. Make extra copies of the blank forms to use with several caregivers or when information changes.

- **Share information about your culture, or life ways, that is important to your family.**

For example, in your family it may be important for your children to play with and care for each other. In another family, children may be encouraged to be independent and play with friends in the neighborhood.



8

Section 8

resources

Defining Universal Precautions

Resources

The following pages contain valuable information and may be used as a resource for families and caregivers.

Universal Precautions Guidelines

In order to prevent disease, it is important to practice good personal hygiene and to take some precautions, especially when working with children. This is sometimes referred to as universal precautions.

The Occupational Safety and Health Administration (OSHA) has established methods people can use to avoid the transmission of infections and disease. By practicing the following methods, you can help yourself, your family, and the child you provide respite for stay well.

Infectious diseases can be prevented with planning and preparation. Always practice good personal hygiene and wash your hands often. Washing your hands is the most important defense to avoid contracting or transmitting an infectious disease. Good health and up-to-date immunizations are important. Always be careful and act as if all people you come into contact with are potentially infected. There is no way to determine if a person is infected just by looking at them.



Defining Universal Precautions

In general, it is good to follow these basic precautions when you provide care:

- **Wear disposable gloves when it is possible that you will contact blood or body fluids. This contact could occur directly from the person or indirectly through contact with soiled clothing, diapers, or other articles.**
- **Remove gloves by turning them inside out beginning at the wrist and pulling them off.**
- **Throw away damaged gloves.**
- **Do not clean or reuse disposable gloves.**
- **Avoid touching any items while you are wearing soiled gloves.**
- **Change gloves when you touch different people.**
- **Wear protective coverings, such as a mask, eyewear, and/or a gown, whenever you may contact body fluids that might splash.**
- **Cover any cuts, scrapes, or skin irritations you may have with clothing or bandages.**
- **Use breathing devices, such as disposable resuscitation masks and airway devices.**
- **Avoid needle sticks.**
- **Perform all procedures in such a way as to avoid splashing, spraying, splattering of body fluids.**



Defining Universal Precautions

- Avoid touching your face after exposure to body fluids before you wash your hands.
- Remove soiled clothing as soon as possible.
- Clean and disinfect all areas soiled by blood or other body fluids.
- Use approximately 1/4 cup bleach to 1 gallon of water to clean and disinfect soiled surfaces and other items.
- Clean up spills immediately.
- If spills are mixed with sharp items such as broken glass, use tongs or two pieces of cardboard to pick them up, not your hands.
- Use an absorbent material to clean up a spill. Discard the used absorbent material.

If you think that you have been exposed to an infectious disease, wash the area of contact immediately. Exposure usually involves contact with potentially infected blood or fluids through a needle stick or the mucous membranes (eyes, nose, mouth) or inhaling potentially infected airborne droplets.

Infectious diseases can typically be transmitted in four ways: 1) by direct contact with an infected person, through body fluids or through contaminated needles; 2) by contact with a soiled object; 3) by inhaling air exhaled by an infected person; 4) from a bite from an animal, an insect, or an infected person.

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Preventing the Spread of Disease

If you are working with a child who has an infectious disease, ask the family how it is transmitted and what you should do to protect yourself. Some infectious diseases that you should be aware of are herpes, meningitis, tuberculosis, hepatitis, and HIV/AIDS. Please refer to the following chart for more information.

How Diseases Are Transmitted

Disease	Signs and Symptoms	Mode of Transmission	Infective Material
Herpes	Lesions, general ill feeling, sore throat	Direct contact	Broken skin, mucous membranes
Meningitis	Respiratory illness, sore throat, nausea, vomiting	Airborne, direct and indirect contact	Food, water, mucus
Tuberculosis	Weight loss, night sweats, occasional fever, general ill feeling	Airborne, direct and indirect contact	Mucus, broken skin
Hepatitis	Flu-like, jaundice	Direct and indirect contact	Blood, saliva, semen, feces, food, water, other products
HIV/AIDS	Fever, night sweats, weight loss, chronic diarrhea, severe fatigue, shortness of breath, swollen lymph nodes, lesions	Direct and indirect contact	Blood, semen, vaginal fluid

Adapted from:

American National Red Cross. (1993). *Preventing disease transmission* [Booklet]. St. Louis, MO: Mosby Lifeline, Mosby-Year Book, Inc.



Preventing the Spread of Disease

Hand Washing

The most important defense against spreading infectious diseases is thorough hand washing with soap and water. Gloves may not always be necessary or even possible to use when reacting to an emergency, but it is extremely important to wash your hands immediately afterward!

There are particular times that you should always wash your hands. It should be done frequently:

- Before putting on a smock in preparation for working with children
- Before drinking, eating, or smoking
- Before handling clean utensils or equipment
- Before and after handling children's food
- Before and after going to the bathroom
- After contact with body secretions, such as blood, urine, feces, mucus, saliva, or drainage from wounds
- After handling soiled diapers, pads, garments, or equipment
- After caring for any child, especially those with nose, mouth, or ear discharge
- After removing disposable gloves
- After removing smock or shirt when leaving the work area



Protocol for Hand Washing

Adapted from:

California State Department of Education. (1983).

Techniques for preventing the spread of infectious diseases [Booklet]. Sacramento, CA:

Author.

Protocol for Hand Washing

Essential Steps

1. Remove all jewelry.
2. Wet hands with warm, running water.
3. Apply liquid soap and lather well.
4. Wash hands, using a circular motion and friction, for 15 to 30 seconds.
5. Rinse hands well under warm, running water.

Key Points and Precautions

Jewelry should not be worn when working with students who require repeated physical contact and care. Microorganisms can become lodged in settings or stones of rings.

Warm water, combined with soap, makes better suds than does cold water. Hot water removes protective oils and will dry skin. Running water is necessary to carry away dirt and debris.

Liquid soap is preferred to bar soap. Bacteria grow on bar soap and in soap dishes.

Include front and back surfaces of hands, between fingers and knuckles, around nails, and the entire wrist area. Avoid harsh scrubbing to prevent skin breaks.

Hold hands under the water so that water drains from wrist area to



Protocol for Hand Washing

6. Repeat steps 3 through 5.

7. Wipe surfaces surrounding sink with
a clean paper towel and discard.

8. Dry hands well with paper towels
and discard towels immediately.

9. Apply lotion as desired.

fingertip.

All remaining bacteria and soil
should now be removed.

Damp surfaces promote the
growth
of bacteria.

Because of frequent hand
washing, it is important to dry
gently and thoroughly to avoid
chapping. Chapped skin breaks
open, thus permitting bacteria to
enter one's system.

Lotion helps keep skin soft and
reduces chapping.

Source:

California State Department of Education. (1983). *Techniques for preventing the spread of infectious diseases*. Sacramento, CA: Author.



References on Adult Learning

References on Adult Learning

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Rossman, M.H., Fisk, E.C., and Roehl, J.E. (1984). *Teaching and Learning Basic Skills: A Guide for Adult Basic Education and Developmental Education Programs* (New York: Teachers College Pr.).

Training Resources

Creative Training Techniques Newsletter
Lakewood Publications
50 S. 9th St.
Minneapolis, MN 55402

(800) 707-7749

<http://www.trainingsupersite.com/publications>



9

Section 9

forms for sharing
information

Sharing Information with Caregivers

Information Worksheets

There are a variety of forms available in this section for families to use in sharing important information with caregivers. Families can use these forms as needed. Some forms provide information specific to the child with special needs and other forms are specific to the needs of siblings also in care. Some forms provide space to include other family and household information. Emergency, health, and safety information sheets and checklists are helpful for caregivers to have.

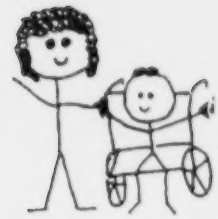
Master copies of all forms and worksheets are included in this section. Families can make copies of forms that several caregivers may need. Families may also keep blank copies and use them when changes occur or new information becomes available.

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Partners Plus Family Manual
Child Development Resources
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DRAFT 10.99



Final Activity

Step 1: Identify training goals.

What do you want your caregiver to learn about your child and family routines?

I want my caregiver to learn about these routines:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____



Step 2: List training methods.

What methods will you use to teach your caregivers?

In order to reach these goals I will use the following methods:

Goal 1: _____

Methods:

1. _____
2. _____
3. _____

Goal 2: _____

Methods:

1. _____
2. _____
3. _____



Goal 3: _____

Methods:

1. _____

2. _____

3. _____

Goal 4: _____

Methods:

1. _____

2. _____

3. _____

Goal 5: _____

Methods:

1. _____

2. _____

3. _____

Step 3:

Use resources to help train your caregiver.

What information will you use to help your caregiver learn?

These are the resources I would like to use:

- ☐ books
- ☐ handouts
- ☐ videotapes
- ☐ audiotapes
- ☐ computer search
- ☐ I develop resources
- ☐ other (please describe)



Step 4: Evaluation

How will you and your caregiver know when a specific skill or routine has been learned?

I will know a specific skill or routine has been learned when we accomplish the following:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____



Essential Information

General Information

Child's Name: _____ Nickname: _____

Address: _____

Phone: _____ Allergies: _____

Age: _____ D.O.B. _____ Height: _____ Weight: _____

Child diagnosis or description of special needs: _____

Health Insurance: _____ I.D. Number: _____

You can reach me at _____

If you cannot contact me, please call:

_____ Phone: _____

Medication

Name of medication: _____

Purpose for medication: _____

Time to be given: _____ Dosage: _____

Pharmacy: _____ Phone: _____

Comments: _____



Essential Information (continued)

Food

Allergies: _____

Cannot have: _____

Acceptable snacks: _____

Meals: _____

Daily Schedule

AM: _____

PM: _____

Nap Time: _____



Health and Medical Information

Child's Name: _____ Date of Birth: _____

Current Health Problems / Needs: _____

Allergies (if any): _____

Child's Physician: _____

Address: _____

Phone: _____

Name and Number of Medical Insurance: _____

Authorization for Emergency Medical Care

_____ has permission to obtain immediate medical care for my child if any emergency occurs when the parent or guardian cannot be located. I understand the child's physician will be contacted if available.

Parent or Guardian: _____ Date: _____



Important Phone Numbers

Mother's Work: _____

Father's Work: _____

Police/Emergency: _____

Fire/Emergency: _____

Poison Control: _____

Doctor's Office: _____

Pharmacy: _____

Hospital: _____

Dentist: _____

Neighbor/Friend: _____

Neighbor/Friend: _____

Relative: _____

Relative: _____

Gas Company: _____

Electric Company: _____

Phone Company: _____

Apartment Manager: _____

Veterinarian: _____

Other: _____



About My Child

Child's Name: _____ Date: _____

What I would like to tell you about my child: _____

Favorite toys or playthings: _____

Special routines (a good-bye hug, snack after school, story for bedtime, etc.)

my child enjoys: _____

Special things (blanket, a pacifier, stuffed animal, etc.) that my child enjoys:

Things that scare my child: _____



Things that quiet or comfort my child: _____

Special things my child does: _____

Activities my child likes: _____

Activities my child dislikes: _____

Personality or behavior style (such as active, quiet, silly, serious): _____

Things that are easy for my child: _____

Things that are hard for my child: _____

Special names or words for people or things that my child understands/uses: _____

Other special information or concerns: _____



About Our Family

The people in our family are: _____

Some things our family does together: _____

Special things each member of my family does alone or with someone else:

Things we would like to do if we had respite: _____

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Dreams for our child with disabilities: _____

Dreams for our family: _____

About Sisters and Brothers

General Information

Brother/Sister's Name: _____ Nickname: _____

Age: _____ D.O.B.: _____ Height: _____ Weight: _____

Allergies: _____

Important health or developmental history: _____

Medications

Name of medication: _____

Purpose for medication: _____

Time to be given: _____ Dosage: _____

Pharmacy: _____ Phone: _____

Prescribing Doctor: _____

Doctor's Phone: _____

Let me tell you about _____



Health and Safety Checklist

Our caregiver is certified in:

- ☐ infant/child CPR
- ☐ first aid

Our caregiver knows where we keep our:

- ☐ medical treatment release forms
- ☐ medical insurance information
- ☐ first-aid kit and book
- ☐ sunscreen

We have provided our caregiver individualized training on:

- ☐ emergency plans
 - ☐ what we would consider an emergency for our child
 - ☐ what we would like our caregiver to do in case of an emergency
 - ☐ where we keep emergency phone numbers
- ☐ fire safety
 - ☐ location of and how to use the fire extinguisher
 - ☐ our fire evacuation plan
 - ☐ location of smoke detector
- ☐ poison safety
 - ☐ where we keep the Poison Control Center phone number
 - ☐ where we keep the Syrup of Ipecac
- ☐ kitchen safety (i.e., stove, appliances, pots on the stove, etc.)
 - ☐ first aid for burns



We have provided our caregiver individualized training on:

- ☐ **hand washing for caregivers and children after toileting and outside time and before food preparation**
- ☐ **medication administration**
- ☐ **our smoking policy**
- ☐ **diaper/toileting routine and diaper disposal**
- ☐ **toy safety (e.g., balloons might suffocate small children, young children might choke on small toys or toys with small parts)**
- ☐ **use of medical equipment**
- ☐ **crib/bed safety**
 - ☐ **young children should sleep on their backs**
 - ☐ **the side rail of a crib should be latched when the child is asleep**
 - ☐ **caregivers should check on sleeping children**
 - ☐ **bottles should be held and not propped for young children**
- ☐ **positioning, exercises, and therapeutic activities**
- ☐ **car safety**
 - ☐ **car seats are available and adjusted for our child**
 - ☐ **correct use of a car seat**
 - ☐ **child should always be in a car seat or fastened seat belt when the car moving**
- ☐ **my child's allergies**
 - ☐ **medical care if my child is exposed to allergens**
- ☐ **safety in the home**
 - ☐ **electrical outlets are covered**
 - ☐ **hot water heater adjusted to 120 degrees or lower**
 - ☐ **guns are unloaded and locked in a cabinet**
 - ☐ **bullets are locked in cabinets separate from guns**
- ☐ **medications, poisonous chemicals, and liquor are kept out of the reach of children**
- ☐ **rubber mats or nonslip surfaces are in showers or tubs children will use**



Step 1: Identify training goals.

What do you want your caregiver to learn about your child and family routines?

I want my caregiver to learn about these routines:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____



Additional Thoughts



Step 2: List training methods.

What methods will you use to teach your caregivers?

In order to reach these goals I will use the following methods:

Goal 1: _____

Methods:

1. _____
2. _____
3. _____

Goal 2: _____

Methods:

1. _____
2. _____
3. _____

Goal 3: _____

Methods:

1. _____

2. _____

3. _____

Goal 4: _____

Methods:

1. _____

2. _____

3. _____

Goal 5: _____

Methods:

1. _____

2. _____

3. _____



Step 3:

Use resources to help train your caregiver.

What information will you use to help your caregiver learn?

These are the resources I would like to use:

- ☐ books
- ☐ handouts
- ☐ videotapes
- ☐ audiotapes
- ☐ computer search
- ☐ I develop resources
- ☐ other (please describe)



Additional Thoughts



Step 4: Evaluation

How will you and your caregiver know when a specific skill or routine has been learned?

I will know a specific skill or routine has been learned when we accomplish the following:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____



Additional Thoughts

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Personalized Training Plan

Child's Name: _____ Date: _____

Routine: _____

Time of Day: _____

Step 1: Training Goal _____

Step 2: Training Methods _____

Step 3: Resources _____

Step 4: Evaluation _____



Additional Thoughts

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Respite Caregiver Profile

Date: _____

Personal:

Name: _____ SS#: _____

Address: _____

Home Telephone: _____ Work Telephone: _____

In case of emergency, notify: _____

Relationship: _____

Home Telephone: _____ Work Telephone: _____

Experience:

Describe experience you have had with children (including your own). _____

Have you ever provided care for children with disabilities?

☐ Yes ☐ No

If yes, please list your experiences: _____



Respite Caregiver Profile, continued

Have you had any courses in early childhood, child development, or child health?

☐ Yes ☐ No

Are you certified in Red Cross First Aid?

☐ Yes ☐ No Date of Expiration _____

Are you certified in Infant/Child CPR?

☐ Yes ☐ No Date of Expiration _____

Do you have a valid driver's license?

☐ Yes ☐ No Date of Expiration _____

Education:

I have completed:

High School _____ Some College _____

College _____ Graduate School _____

Degree or Major (specify): _____

Other training/education: _____

Employment:

Current Employer: _____

Position: _____



Respite Caregiver Profile, continued

Interests: (Check all that apply)

I am willing to care for children ages

birth - 2 _____ 2 - 5 _____ 5 - 8 _____ over 8 _____

I am willing to provide care (check all that apply):

☐ at my home	☐ weekdays
☐ at child's home	☐ weekends
☐ during the day	☐ overnight
☐ during evenings	☐ anytime

When I provide care, I will care for:

☐ only the child with disabilities
☐ the child with disabilities plus siblings
☐ the child with disabilities and other children in my care
☐ the child with disabilities and my own child/children

I would prefer to provide care:

☐ as a volunteer
☐ in exchange for a service (i.e., transportation, lawn care, meals, etc.)
☐ for an hourly rate of \$ _____
☐ for a negotiable hourly rate

How far are you willing to travel to provide care? (Check all that apply.)

☐ Williamsburg/James City County	☐ Hampton
☐ York County	☐ Poquoson
☐ Newport News	☐ Gloucester



Respite Caregiver Profile, continued

References:

Please provide the names, addresses, and phone numbers of two persons we may contact who have known you for more than 1 year (excluding relatives or roommates).

Name: _____ Phone: _____

Address: _____

Name: _____ Phone: _____

Address: _____

I am most interested in providing respite care because _____

Thank You!



Reference Check

Date: _____

Name of Potential Caregiver: _____

Name of Reference: _____ Phone: _____

1. How do you know _____ ?
(put name of potential caregiver here.)

2. How long have you known _____ ?

3. What words best describe _____ ?

4. How would you best describe how _____
relates to children?

5. Describe what you think are _____'s strong
points in working with children with special needs and their families?

6. Are there any other comments about _____
you would like to make?

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Additional Thoughts

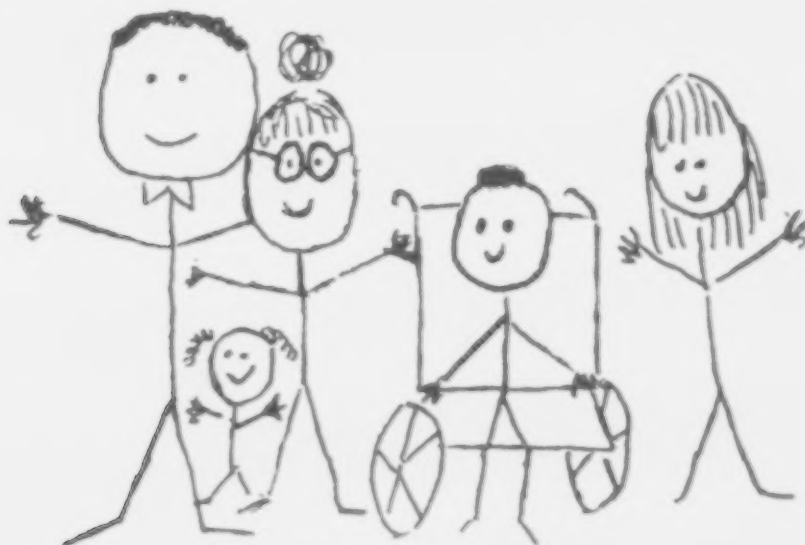
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Partners *Plus*

Caregiver Manual



Families and Caregivers in Partnerships
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Partners *Plus*

Families and Caregivers in Partnerships: Caregiver Manual

By

Lisa L. Ownby, M.S.W.

Amanda C. Hooke, M.S.W.

Dee Wylie Moore, B.S.

Corinne W. Garland, M.Ed.

The **Caregiver Manual** is part of a series of resources in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**. The rest of the series includes the **Community Planning, Trainer's Workshop, and Family Manuals**, created by Child Development Resources.





Revised from the original

PARTners Plus: Parents as Respite Trainers Caregiver Training Manual

Authors: Corinne W. Garland, Barbara A. Kniest, Karen S. McKinney, Dee W. Moore, and Nancy Tyree (1995)

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Post Office Box 280
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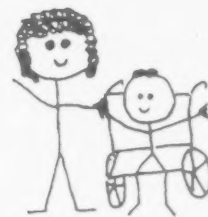
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Step 1: Identify training goals
Step 2: List training methods
Step 3: Use resources to help train your caregiver
Step 4: Evaluation



Notes on this Section

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Caregiver Manual

introduction

Partners Respite Model

The Partners Model of Respite Care...

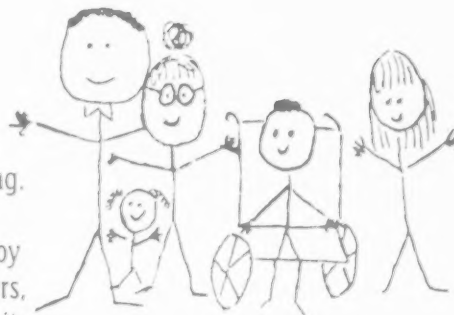
Helps families of children with special needs find and train their own respite caregivers.

Through training and support, families and caregivers build long-lasting, successful respite relationships.

Introduction

Like all families, families of children with special needs want and need time away from the demands of parenting. **Respite**—or temporary child care for children with disabilities or chronic illness—gives families time to enjoy an evening out by themselves, with other family members, or with friends. However, for these families, finding respite care is not as simple as calling a neighborhood babysitter. These families need caregivers who understand their children's special needs.

When the staff at Child Development Resources (CDR) spoke with families about what they wanted in a respite program, the message was clear. Families wanted to choose and train their own respite caregivers. They wanted affordable care that was as simple to schedule as calling the neighborhood babysitter. And, families wanted caregivers who were trained to provide care.



A Brief Partners History

In response to families and with support from the Virginia Institute for Developmental Disabilities (VIDD), a University Affiliated Program at Virginia Commonwealth University in Richmond, Virginia, CDR developed a pilot project that was low-cost, family-directed respite care called **PARTners: Parents As Respite Trainers**.

CDR was awarded, in 1994, a three-year grant from the U.S. Department of Education, Office of Special Education Programs (OSEP), Early Education Program for Children with Disabilities (EEPCD), to build on the pilot and to develop a model of respite that could be replicated in other communities. The project, **Partners Plus: Families and Caregivers in Partnerships**, provides a model for families to use in finding and training respite caregivers. This model encourages families to use available, **natural** family and **community** supports to meet their respite needs.

Within this model, Partners broadly defines the terms *respite* and *caregiver*. For example, respite can take place in a family's home, a caregiver's home, or in before and after school, recreation, camp, or other children's program. A caregiver can be any individual who *provides respite care* to a child with special needs or *includes* a child with special needs within an existing community program.

Partners Plus provided training to more than 200 families and caregivers in a five-city, three-county area of eastern Virginia. Partners usually conducted the six hour Partners Plus workshop for families and caregivers in one day. Sometimes when it was more convenient for a group, Partners conducted the workshop in two parts on separate days. This flexibility ensured that Partners adapted training



A Brief Partners History

to fit the schedules of families and caregivers who are generally most receptive to training during nontraditional hours such as evenings and Saturdays. Families attending the workshop learned to provide their own caregivers with personalized training based on their children's daily routines. Families either came to training with their own caregivers, met caregivers through the workshop, or through other project activities.

The Partners Project resulted in the development of four manuals designed to help communities, trainers, families, and caregivers use the Partners model. The **Caregiver Manual** is one of four in a series of manuals that Partners has conveniently packaged together in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**. Besides the set of manuals contained in the guide, you can purchase the **Family and Caregiver Manuals** separately from the Partners Plus program through CDR.

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Norge, VA 23127-0280

Phone (757) 566-3300

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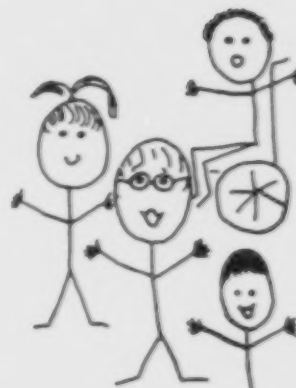
Partners Model: 5 Steps

The Partners Model: A New Model of Respite Care

Partners programs provide group training and continuing support to families and potential caregivers. The Partners model contains five steps:

The Five Steps of the Partners Model

- 1. Recruit Families and Caregivers*
- 2. Conduct Partners Workshop*
- 3. Help Families Choose Caregivers*
- 4. Guide Families as they Train their Own Caregivers*
- 5. Provide Continuing Support*



Step 1: Recruit Families

First, programs **recruit** families and potential caregivers to participate in Partners. Community awareness activities invite potential participants to a Partners workshop. Information about the workshop and the Partners program is distributed through parent groups, newspapers, radio, flyers, word of mouth, etc.



Partners Model: 5 Steps

Step 2: Conduct Partners Workshop

Next, programs *conduct the Partners workshop*. During the six-hour workshop, families learn how to find, screen, and interview caregivers for their children. In addition, they learn to structure training for their own caregivers based on the specific needs and daily routines of their individual children. Caregivers learn basic information about caring for children with special needs. During the workshop, caregivers are preparing to be active in their work with families, reflecting on their motivations for becoming respite caregivers and identifying their own learning needs for personalized training. Partners **Family** and **Caregiver Manuals** provide participants with useful resources to actively engage in during the workshop and to use as resources as they move through the next steps of the model.

Step 3: Families Choose Caregivers

After the workshop, Partners programs provide continuing support as *families choose caregivers*. Families frequently identify respite caregivers within their own circles of natural support. If families are unable to identify their own caregivers, Partners will assist by providing social and educational events that will help families and caregivers meet. During interviews, families and caregivers negotiate how respite occurs. Respite may be in-home or out-of-home and reimbursement for care can be flexible. Care may be provided for a fee, voluntarily, or in exchange for another service, such as yard work.

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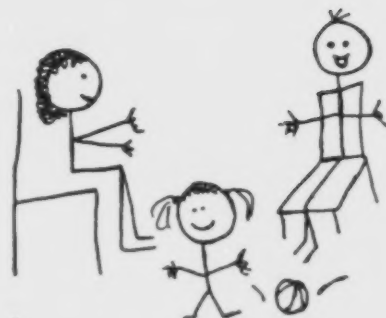
Partners Model: 5 Steps

Step 4: Families Train Caregivers

Once families and caregivers decide to work together, **families train their own caregivers**. This “personalized training,” discussed during the workshop, is organized by families with help from Partners staff if needed. Families decide what routines caregivers need to learn and work with caregivers to determine how training will occur, thus forming true partnerships necessary for successful respite.

Step 5: Provide Continuing Support

As families and caregivers work together to develop a personalized respite training, the community Partners program **offers continuing support**, information and guidance. The Partners program is available to support families and caregivers in various ways as they begin their respite relationship. Partners staff members respond to requests for help and support from both families and caregivers. For example, Partners may help families and caregivers with screening, interviewing, developing personalized training plans, and providing educational opportunities.



Partners Replication Process

Partners Plus Replication Process

The Partners Plus **Community Planning Manual**, contained in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care**, helps communities use the Partners model of respite care. Each community interested in model replication develops a plan for collaboration among agencies, organizations, and individuals in order to implement the model. Community resources and supports are needed to sustain the model, to create a home for the program, and to ensure continuation.

The community replication process includes four major steps:

- 1. Identifying the site for replication*
- 2. Planning for replication*
- 3. Implementing the model*
- 4. Evaluating the model*

The Partners Plus **Community Planning Manual** is a step-by-step guide for the replication process outlined in the flowchart on page xvi.

Your community will be a good candidate for replication if you have the following:

- support from agencies that provide, or are involved with, respite services

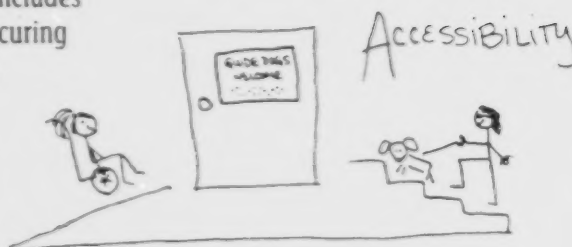
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Partners Replication Process

- knowledge of current respite funding to support families without financial resources
- support and commitment from local early intervention programs, mental health or mental retardation programs, and/or family support programs

Each community needs to develop a *plan for replication*. Awareness activities aimed at a broad array of agencies, organizations, and individuals help strengthen community support. The creation of an advisory committee brings expertise and resources that will ensure a quality program. The replication plan includes finding a home for the program and securing staff responsible for implementing the program. Formal or informal interagency agreements and perhaps grant proposals may be necessary for community replication.



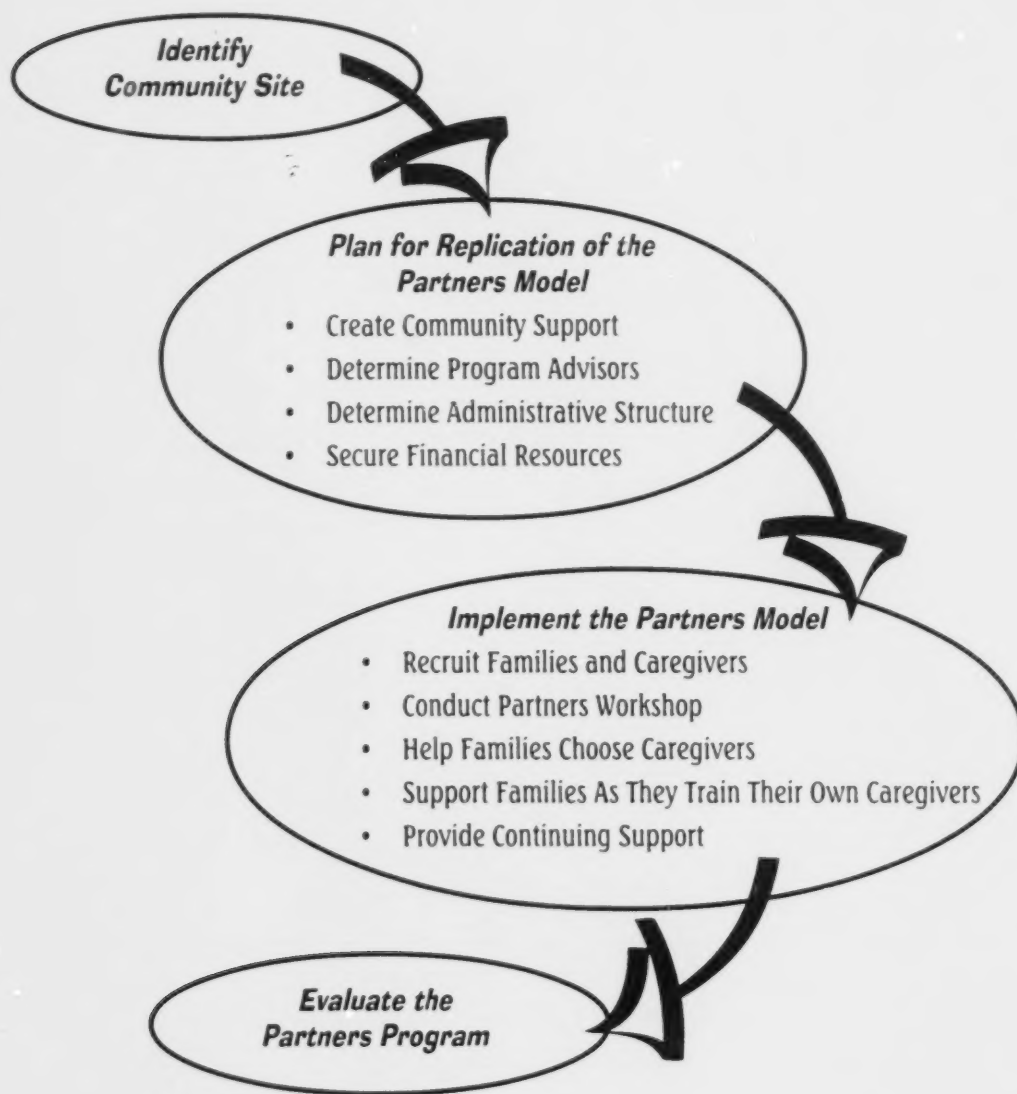
The **Community Planning Manual** provides strategies and materials to help communities develop and *implement* the respite care program. The **Trainer's Workshop Manual**, accompanying the **Community Planning Manual**, includes agendas, overheads, and suggestions for what to say during the Partners workshop. There are also suggestions for the kinds of resources that are needed by families and caregivers in order to foster and maintain long-term relationships.

Communities that replicate the Partners model gather information from families and caregivers to *evaluate* the quality and usefulness of training and support.



Partners in your Community

Partners Community Implementation Process



Partners Plus Manuals

Partners Plus Manuals

There are four manuals in the **Partners Plus Families and Caregivers in Partnerships, A Family-Centered Guide to Respite Care** that support the Partners Plus replication process:

1. The **Family Manual**
2. The **Caregiver Manual**
3. The **Community Planning Manual**, and
4. The **Trainer's Workshop Manual**.

The **Family** and **Caregiver Manuals** are used in the Partners workshop for families and caregivers. These manuals include resources that families and caregivers can continue to use as they develop partnerships for respite care for children with special needs. The **Community Planning Manual** helps communities develop a community-based, family-centered respite system. The **Trainer's Workshop Manual** contains overheads, forms, and "helpful hints" for conducting Partners workshops.

The **Family Manual** is easy to follow and guides families in choosing and training their own respite caregivers. Families use their children's daily routines to develop training plans for caregivers. The manual includes information about respite, communication, building partnerships, selecting caregivers, and developing personalized training. There are worksheets, resources, and forms that can be duplicated for future use.



Partners Plus Manuals

The **Caregiver Manual** provides caregivers with basic information on caring for young children with disabilities and supporting families. This manual includes information about respite, communication, building partnerships, disabilities awareness, child development, children with special needs, and personalized training with families.

The **Community Planning Manual** provides communities with a step-by-step guide to replication of the Partners model. By following each step, communities and families can work together to develop respite care programs. The manual contains forms and materials to assist with replication of the model.

The **Trainer's Workshop Manual**, used in conjunction with the **Community Planning Manual**, helps community trainers to conduct the six-hour Partners workshop for families and caregivers.



1

Section 1

About respite

About Respite Care

Respite . . . Rest, Relax, Renew

Often we are asked, *What is respite care?* Our first response is simple: respite care is temporary care for a family member with special needs.

Families have told us in many different ways what respite means to them:

- Time to readjust.
- A break from the routine.
- Rest in spite of demanding circumstances.
- I feel refreshed and renewed when I come back from respite.
- Think of a candle that slowly burns: the flame flickers and goes out, and, just as a candle, we need to be relit, too.

— *Partners Plus Families*



More About Respite Care

Respite care is a term used to describe occasional care for an individual with special needs. Respite care programs began in the 1960s when people with disabilities began receiving care in their homes and communities instead of in institutions. Acknowledging the importance of respite care to families providing home care, Congress passed federal legislation providing funds to help communities develop respite care programs.



Who Needs Respite?

The 1986 federal legislation that provided funds to set up model programs of respite care defines respite care as in-home or out-of-home temporary, nonmedical care for families who have children (young and/or adults) with disabilities or chronic or terminal illnesses. More simply, respite care is any type of temporary care provided to a person with a disability or special health care need.

There are a variety of respite models, each designed to meet the unique needs of families. Descriptions of these models are included in Section 9 of this manual (see ARCH Fact Sheet Number 2).

Families Who Need Respite

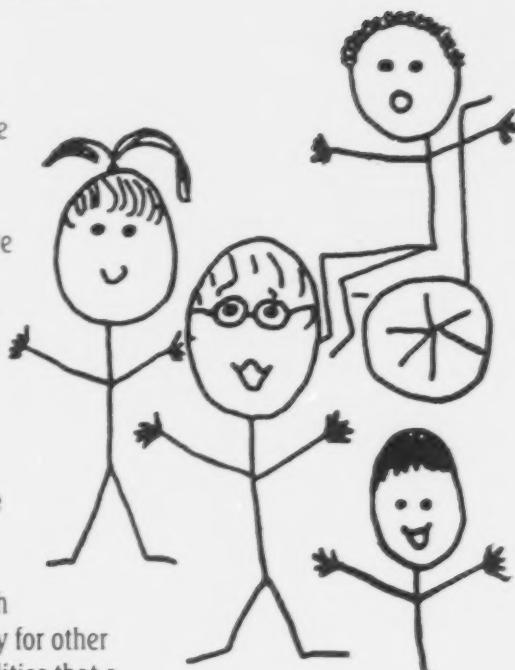
Families who have children with special needs are very much like other families. Like all families, they have values, beliefs, interests, concerns, needs, and dreams. However, families of children with special needs also have special challenges that affect the way they live. Here are some things we have learned from families.

- Like other parents, parents of children with special needs are concerned about their children's
 - development,
 - health,
 - education,
 - training, and
 - social life.
- Parents of children with special needs must put forth extra effort to help their children.



Who Needs Respite?

- Parents of children with special needs are often very knowledgeable about their children's disabilities and have learned some of the best ways to help them.
- Like other parents, parents of children with special needs are concerned about
 - the needs of all of their family members,
 - the education of all of their children,
 - the activities of all of their family members, and
 - their jobs.
- Daily routines for families of children with special needs are similar to those of other families.
- Families of children with special needs have hopes and dreams that are like those of most other families.
- Children with special needs and their brothers and sisters can grow up healthy and lead productive lives.



Children Who Need Respite Care

A child who needs a respite caregiver is one who has special physical, emotional, or health needs that require care beyond that necessary for other children. The kinds of special needs or disabilities that a child may have can vary greatly from hearing impairments that require a child to communicate through sign language to mental retardation to terminal illness.



Benefits of Respite Care

There is no one approach to caring for children with special needs but there are some basic guidelines:

- Children with special needs are more like other children than they are different.
- Children with special needs can and do learn.
- Children with special needs should be encouraged to do as much for themselves as they can.
- Children with special needs thrive when given love, acceptance, and necessary support.
- Like other children, children with special needs benefit from healthy play and recreation, friendships, being outdoors, and going places.

Benefits of Respite to Families

Respite care gives parents a break from the daily demands of parenting a child with special needs, and offers much more.

Rest to recuperate, rejuvenate, replenish, rejoice

Enjoying movies, dinner, fishing

Shopping for groceries, school, self, kids, family

Pampering at a hair salon or gymnasium or having lunch with a friend

Interests to pursue such as hobbies, sports, community activities, and education

Time to spend with siblings, other family members, and friends

Everything or **anything** families want to do!



Benefits of Respite Care

Benefits of Respite to Children

Respite is also beneficial to children. Some of these benefits include the following:

- Relief that their parents finally got out
- Exploring new faces and activities
- Special friends of their own
- Parents who feel rejuvenated
- Interacting with other adults and children
- Time to be independent from their family
- Educating each other about differences and similarities

Benefits of Respite to Caregivers

Respite also benefits caregivers in many ways.

- Really great children and families to get to know
- Especially rewarding to know that they are making a positive difference for a family
- Self-improvement and growth through learning new skills and ideas
- Positive attitudes about themselves and about people who are different from themselves
- Involvement with children, families, and communities
- Thoroughly appreciated by families who need them
- Everything caregivers want respite to be!

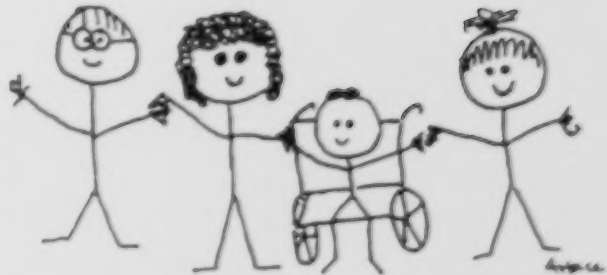
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Barriers to Respite Care

Who Can Be Respite Caregivers?

- Neighbors
- Friends
- Relatives
- Community Program Staff
- Church Members
- Students
- Bus Aides
- Anyone with a desire



Why Don't Families Use Respite Care?

Despite the benefits of respite for everyone, many families do not use respite care. Families have identified various reasons:

- It is difficult to find someone to provide temporary care.
- We are afraid to leave our children with strangers.
- We fear that respite caregivers lack adequate training.
- We sometimes feel guilty about leaving our children.
- It is difficult to find community programs for respite care.
- It is too disappointing when caregivers cancel frequently.



Keys to Successful Respite

Keys to a Successful Respite Program

Families say a successful respite program must have these elements:

- Helps families feel comfortable
- Gives families options for how they want to participate
- Gives families options for times to be involved
- Is family centered
- Supports families in developing new linkages
- Supports families in developing individualized caregiver training
- Asks families if they want to be involved in program planning
- Gives families access to dependable, reliable caregivers

Source:

Reprinted with permission of ARCH National Respite Network and Resource Center, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514:

Access to Respite Care and Help (ARCH). (1992). *Respite care for children with developmental and/or physical disabilities: A parent's perspective*. Chapel Hill, NC: Author.

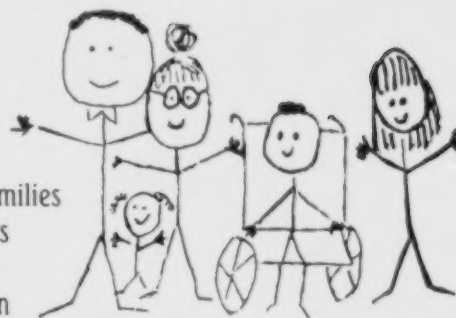
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Describing Family-Centered

Description of *Family*

What Do We Mean by Family? We all come from families. Families are big, small, extended, nuclear, multigenerational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, or as permanent as forever. We become part of a family by birth, adoption, marriage, or from desire for mutual support. As family members, we nurture, protect, and influence each other. Families have strengths that flow from individual members and from the family as a whole. Each family is a culture unto itself, with unique values and its own way of realizing dreams. Together, our families are the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states, and nations.



Source:

New Mexico Children's Continuum/New Mexico Advocates for Children and Families. (1990). *First steps to a community*. Albuquerque, NM: Author.

Description of Family-Centered Philosophy

Family centered means the recognition that the family is the constant in a child's life and that service systems and the personnel must support, respect, encourage, and enhance the strengths and competence of the family.

Source:

Shelton, T., Jeppson, E., & Johnson, H. (1987). *Family-centered care for children with special health care needs* (2nd ed.). Washington, D.C.: Association for the Care of Children's Health.



Family-Centered Care

Family-Centered Care

What does providing family-centered care mean?

- Recognizing that a family will always be in a child's life while services and professionals will change
- Making it easier for families, volunteers, and professionals to work together in hospitals, homes, and community care
- Sharing information, ideas, and concerns among families, volunteers, and professionals as a team
- Honoring the diversity of families, knowing that we each bring richness to the world we live in through our cultures and the ways we live our lives
- Recognizing and respecting that families meet their own needs in different ways
- Designing services that are flexible, that are easy for families to use, and that meet each family's individual needs
- Appreciating families as families and children as children and recognizing that they have a wide range of strengths, concerns, emotions, and dreams beyond their needs for specialized health and developmental services and support



Source:

Reprinted with permission of the Association for the Care of Children's Health, 19 Mantua Road, Mt. Royal, NJ 08061:

Shelton, T. L., & Stepanek, J. S. (1994). *Family-centered care for children needing specialized health and developmental services*. Washington, DC: Association for the Care of Children's Health.

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Partners Respite Model

A New Respite Model: Partners

The Partners model of respite care is designed to increase respite options for families of children with special needs by helping families find and train their own respite caregivers.

Respite can be provided in:

- Families' homes
- Caregivers' homes
- Community respite programs
- Before and after school programs
- Recreation programs
- Camps

Respite can take place anytime, any place, with anyone in order to support families in meeting their needs.

Partners is a natural and family-centered model that involves families in the design, implementation, and evaluation of respite care. The model encourages the development of community collaboration among agencies and parent, religious, and/or support groups to support this model and to create a home for the program.

Together, families and caregivers attend group training. Families learn how to recruit, screen, interview, and train caregivers. Caregivers are provided with basic education in caring for children with special needs. After group training, the next step is for families and caregivers to match up and begin individualized training. The **Family and Caregiver Manuals** are provided to families and caregivers to use as a resource to help them through this process.

Partners. . .

- *is a family-centered model.*
- *offers families many choices.*
- *allows families options for how they can participate.*
- *supports families in finding caregivers.*
- *supports families in training their own caregivers.*
- *helps families build necessary skills to communicate respite needs.*
- *helps families build long-term caregiver relationships.*
- *expands respite options for families.*



Partners Respite Model

The Partners program provides support to families and caregivers to help them begin building respite relationships. When a family cannot find a respite caregiver within their own circle of natural supports, they can choose from the pool of caregivers recruited by Partners Plus or can attend social and educational events coordinated by the program to help families and caregivers meet and match up.

With the Partners model, families and caregivers have choices about how respite care is provided. Respite may be provided in-home or out-of-home. Care may be provided for a fee, in exchange for another service, or by a volunteer. These decisions are made between families and caregivers. Families may also choose to develop a parent (or family) cooperative in which they care for each other's children. Families decide what kind of training caregivers need and work with caregivers to determine how training will proceed, forming a true partnership necessary for successful respite.

Partners Model of Respite Care

- Step 1** *Recruit families and caregivers*
- Step 2** *Conduct Partners workshop*
- Step 3** *Support families in choosing caregivers*
- Step 4** *Guide families as they train their own caregivers*
- Step 5** *Provide continuing support*

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Section 2

building partnerships:
communication

Building Partnerships: Communication

Building Partnerships

Respite care is not just about giving out medicine. It is a whole dialogue and relationship with a family.

— Partners Plus Caregiver

Partners Plus supports strong relationships between families who have children with special needs and their caregivers. In partnerships, families and caregivers respect one another and commit to working together.

Partnerships actively prevent caregiver burnout and family disappointment. Partnerships are built with open and honest communication and understanding. Sections 2 and 3 of this manual explore building partnerships through communication and collaboration.

Building Partnerships Through Communication

Good communication strengthens the relationship between family and caregiver.

Honesty and openness in communication help build cooperative relationships over time!

What does communication mean?

- *Sharing information, ideas, and feelings that increase understanding about yourself and others*
- *Listening carefully to each other in ways that develop partnerships and promote the best care for children*
- *Sharing common values and traditions and talking about similar experiences to strengthen your relationship with each other*
- *Appreciating differences to strengthen mutual respect*



Using More Than Words

Building Partnerships: Communication

Clear communication is one key ingredient in building partnerships. We send messages all the time, even when we are not speaking.

Communication is . . . 7% Words

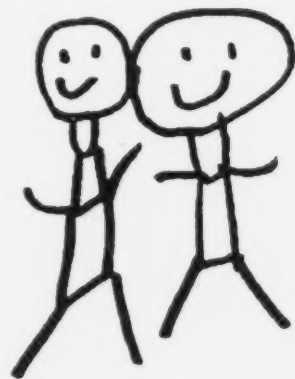
Research shows the words we use or choose are important in gaining understanding. In communicating with another person, we need to use language that is common to both the speaker and the listener.

38% Voice

The voice we hear is more important than the words we use. We need to be aware of our expression and tone of voice. We use our voices to help express things like sincerity, conviction, requests, and concern.

55% Facial and Body Language

Our face and body are the most powerful means of communication. Smiles, frowns, raised eyebrows, widened eyes, tears, laughter, scrunched-up faces, and wrinkled noses all tell us very different things.



Source:

CareerTrack. (1992). *How to deal with difficult people: Video workbook*. Boulder, CO: CareerTrack Publications.



How Do You Feel?

How Do You Feel?

Facial expressions can communicate a lot about our thoughts and feelings. Use the blank circles to draw faces that send messages to others.



Anxious

Angry

Bashful

Bored



Confident

Thinking

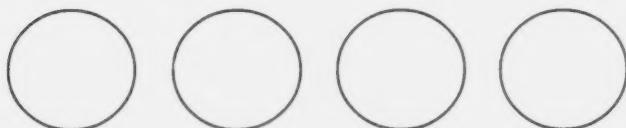
Confused

Scared



Innocent

Relieved



*Adapted from
feelings posters
by:*

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Understand the Cycle

Six Messages of Communication

Communication is a cycle. As you communicate with others, think about the many places that communication can break down. Does the other person really understand what you mean? Each communication contains the possibility of six separate messages:

- What you mean to say
- What you actually say
- What the other person hears
- What the other person thinks he hears
- What the other person says
- What you think the other person says

Adapted from:

Bassett, L. C., & Metzger, N. (1986). *Achieving excellence: A prescription for health care managers*. Gaithersburg, MD: Aspen Publishers.

What You Need to Know About Communication

- **Communication is the way we send and receive messages.**

Most people use a combination of verbal and nonverbal communication. Being aware of and sensitive to the different ways people communicate helps to build mutual respect and understanding between families and caregivers.



Learning To Communicate

- Our ways of communicating are influenced by our culture.

Our culture determines much about how we think, feel, act, and communicate with others.

- The term *life ways* refers to the many ways we are influenced by others and by our environment throughout our lives.
- Gestures, silence, body movements, distance, and emotional expressiveness are other ways of communicating that are influenced by our cultures and life ways.

For Example:

- Too much silence makes some people uncomfortable.
- Too few pauses while talking may disturb others.
- To be comfortable, some people need some distance between themselves and others.
- Lots of eye contact is important in establishing trust for some.
- For others, too much eye contact is considered disrespectful.
- A relaxed open body posture, with arms not crossed in front, invites others to talk.
- Leaning slightly forward shows interest.
- Sitting up straight helps you look more alert.
- Much of our communication is done without words.
- Our eyes are used to communicate.

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Connecting without Words

For Example:

A look can be exchanged between parents that says, *It's time to leave*, or a look from a mother's eyes to her child can communicate the message, *You need to behave*.

- When people have similar experiences, we sometimes presume a shared understanding of feelings or thoughts.

For Example:

When a parent at an oncology clinic says to another parent in the waiting area, *My child is receiving chemotherapy for leukemia too*, an exchange that takes place by looking at each other in the eyes can send a message of shared understanding, even though each family's experience is unique.

Depending on their life ways, families use more spoken or written words to communicate. Words help us to be direct, exact, and logical and encourage others to say more. The following is an example of a family and caregiver interview in which words are used to encourage a response.

Caregiver: I want to provide respite because I enjoy being with children.

Family: That's great! You like being with children.



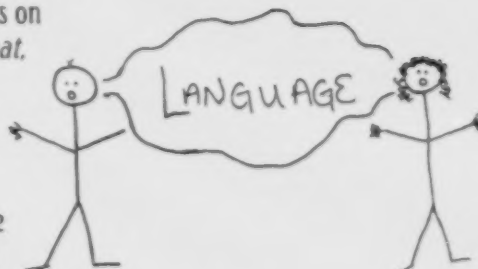
Methods of Communication

Caregiver: Yes, I miss being a parent and my grandchildren live in another state. When my children were young, I enjoyed planning activities for them.

Family: What type of activities do you like to plan for children?

- Spoken and written words are helpful in finding out about a person's feelings and attitudes.

Questions that cannot be answered with a yes or no encourage others to talk about what is on their mind. Use words like *how*, *why*, *what*, and *tell me*.



For Example:

Family: On your first visit to my home you watched me feed Crystal and I gave you some information to take home to read. Why don't you try feeding Crystal today?

Caregiver: I think I should watch again to make sure I remember how.

Family: You seem uncomfortable trying this now. Tell me about your concerns.

Caregiver: I remember how much Crystal coughed when you fed her and how much she gagged. I am afraid I will choke her. I think you need someone with nursing skills to take care of your child.

Matching Life Ways and Styles

Family: Perhaps we need to talk again about why Crystal has difficulty eating and why she might cough or gag. I want you to understand Crystal's special needs and to feel comfortable in caring for her. I am here to help while you feed her. Let me show you again. Then you try.

- Using words like *describe*, *show me*, and *tell me* can help determine if a caregiver has learned a skill or has understood the instructions.

For Example:

Family: How did your first day go?

Caregiver: I had trouble using Jared's wheelchair when we went outside.

Family: Tell me what gave you trouble.

Sharing Information

To ensure a successful respite relationship, families and caregivers need to openly share information. This is necessary in initial training and throughout the relationship.

Information can be shared in many ways:

- Keep and share a respite journal.
- Plan information you want to share when you get together.



Tips for Caregiver Interaction

- Allow time to meet with each other before respite care takes place.
- Allow time to talk after respite care.
- Make necessary decisions promptly.
- Resolve conflicts in a timely way.
- Solve problems together.

Tips for Communicating with Your Caregiver

- Communication is essential and is an important part of maintaining a successful relationship.
- Give clear instructions and make sure your caregiver understands what you have said.
- Provide immediate feedback to your caregiver during all training activities.
- Put yourself in the caregiver's place; remember, you once had to learn new ways to care for your child.
- Let your caregiver know when respite care goes well and when you are pleased.
- Be positive. When changes are necessary, tell your caregiver in a positive way.



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Section 3

building partnerships:
working together

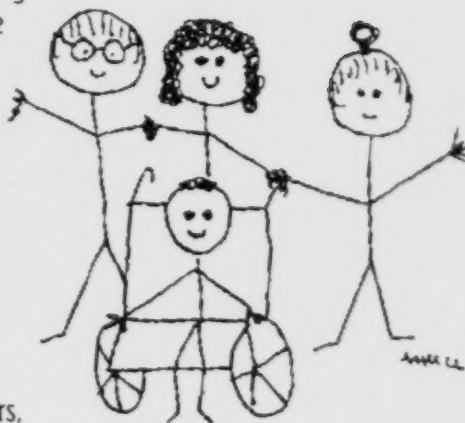
Partnerships: Working Together

Anyone with a desire to help families of children with special needs can become a capable respite caregiver. At first, many parents do not know how to care for their children with special needs, but gradually they learn. Through willingness to learn from families, respite caregivers can do the same.

Many respite caregivers, although not parents of children with special needs, can appreciate the benefits of getting a break from caring for children. Some people have life experiences that help them become more comfortable as respite caregivers. They may know someone who has special needs—a friend, a student, a classmate, someone at church, or a family member. The most important quality a respite caregiver has is a positive attitude.

We know children and their families depend on each other. Children depend on their families for love, support, and guidance. The family is a continuing influence in their child's life, whereas friends, neighbors, and caregivers change. Parents know their own children best. Families and caregivers need to know how to work together for successful respite care.

While caring for children with special needs can be a wonderful experience for both families and caregivers, it can also be stressful. It is helpful for families to understand the challenges that caregivers face when caring for children with special needs. Caregivers may feel unimportant or underappreciated. They may be uncomfortable with the tasks they are given. The material on the following pages can help you learn from each other.



One Family's Story

Family and Caregiver Perspectives

Families and caregivers can better understand each other by listening to personal experiences. Several perspectives from families and caregivers are included in this section.

The first story is "Welcome to Holland" by Emily Pearl Kingsley. From that story, you will see how one parent, whose child was born with a disability, saw her life changing. Other stories from families and caregivers are also included. Your story may look very different from these. To get a better understanding of one another we encourage families and caregivers in partnerships to share their unique stories.

"Welcome to Holland"

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . .

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans—the Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes in and says, "Welcome to Holland!"



"Welcome to Holland"

"Holland?!" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy!"

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

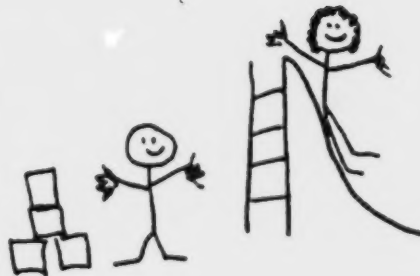
So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people that you would have never met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for awhile you look around and you begin to notice Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned." The pain of that will never, ever, go away because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't go to Italy, you may never be free to enjoy the very special, the very lovely things in Holland.

— *Emily Perl Kingsley, 1981, Parent*



"A Personal Story"

A Personal Story

Although my son Matthew died, he is still a part of my life. Matthew made a difference in who I have become. At first I shared the same thoughts and feelings that Ms. Kingsley expresses in "Welcome to Holland." After Matthew was born, my family began to live a different kind of life. It was often very difficult for us. We learned a lot about ourselves and we learned a lot from Matthew. We discovered that our love for Matthew and each other was very powerful. We found that we had many hidden strengths. Our family grew stronger ties with our community. Friends, neighbors, professionals, and even strangers helped us in many different ways. There were two very important things we wanted most from others. One was for others to accept our son. The other was respect for our family's decisions in how to live with our child's chronic illness and disabilities.

After getting to know Matthew, his disabilities did not seem like the most important part of his life. My four-year old daughter taught me to love Matthew just because he was a baby. To my daughter, Matthew was always her baby brother, not a baby with disabilities. She never noticed much difference until she got older. Other families of children with disabilities have shared some similar thoughts with me. Many say they wish others would stop seeing only their child's wheelchair, their tubes, the way they talk differently or look different. At times, families want professionals to stop testing their



"A Personal Story"

child long enough to get to know him or her as a child, a child with a name and family.

When I describe my son, I tell people that Matthew was small and easy to carry places. Daily care for Matthew was like taking care of an infant. He had a crooked little smile. His sister could make him smile most often, but others could sometimes if they gave him a gentle squeeze around his shoulders. His favorite game was to repeat sounds that we made to him. Matthew's favorite toy was a baby's beaded teething ring. He liked to fall asleep on his father's shoulder. Matthew's greatest strength was that he could teach others about the power of the human spirit.

In describing Matthew's disabilities I would say that Matthew had a genetic impairment called trisomy 22. Trisomy 22 is an extra chromosome that affects every part of the body. He never grew to be more than five pounds and twenty-three inches. There was a hole in the roof of Matthew's mouth that made sucking and feeding very difficult. We fed Matthew with a tube that we put down his throat and into his stomach. His heart and all other systems in his body did not work well. Matthew was delayed in all areas of his development. With help from professionals we learned to deal with all of his special needs.

Getting information about our son's disability through an early intervention program and from medical practitioners helped us understand how to care for our child. A service that helped our family a

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"Father of a Child with Special Needs"

lot was respite care. My family and I needed time separate from being with Matthew. I wanted to give all my attention to my daughter at her soccer games. My husband and I needed time together to laugh and have fun. I needed time to rest physically from the frequent round the clock feedings required for Matthew. I needed emotional rest from the constant concerns I had for Matthew. A few friends, neighbors, and community agencies helped us get respite from time to time. One agency linked us with a community family who was willing to give me a few hours of respite each week. Just those few hours gave me the relief I needed to renew my energy and continue to care for Matthew.

— Dee Moore, 1995, *Parent*

Being a Father of a Child with Special Needs

Being a father of a special needs child takes a special person. There are times when you just want to give up but you know that you can't. The doctors gave my son 3 days to live and now my son is 3 years old. It's a blessing from God that he's still with me today. One thing that I try to remember is to treat him like a normal child. I take him to amusement parks on vacation and to the mall, just to name a few places.

There are times when it's very difficult being a father of a special needs child. I have to watch my



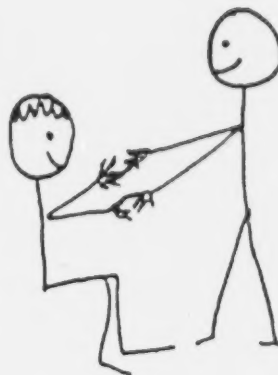
"Father of a Child with Special Needs"

child go through intensive surgeries just to be able to eat and breathe like you or I. There are times when all you can do is just listen to your child cry uncontrollably, but overall being the father of a special needs child is a blessing from God. If you're a dad and wonder what it's like to be a dad to a special needs child, it is like taking care of three children.

— Lamar Ramsey, 1997, *Parent*

A Parent's Perspective

From the moment Kieren was born, I knew something wasn't quite right. He used to cry all the time. He was totally fearless, and I could leave him with anyone. He didn't seem to care if I was there or not. As he grew older, he used to run away all the time. We had to lock all the doors and never let go of his hand when we were out or he was gone and he didn't come back. If he saw something he liked, he would jump up and down, flap his hands, and shriek. Looking back, there were a lot of warning signs but I didn't know what I was looking for. I just knew that something was not right. I think one of the worst things about not knowing he had high-functioning autism was that no one else seemed to think there was a problem (or so they led me to believe). I would say to family and friends that I was concerned, and they would tell me, "Oh, all children do that," and dismiss it, and in the end I was beginning to doubt my sanity.



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"A Parent's Perspective"

When he was 2, we were stationed in Germany, where 9 months later my daughter was born. I think it was a blessing in disguise that we were in that country as they test routinely for cystic fibrosis in all newborns. We found out when she was 6 weeks old that she had it. She was having some problems but the doctors told me this is normal, all babies do these things. Where have I heard that before?!

So we were sent back to the states so that we could get the health care she needed. Once she was relatively stable, I turned my attention back to Kieren. I made an appointment with the school division to get Kieren assessed to see if he was eligible for the special education program. During all the appointments I remember thinking he is doing really well today and they are going to think I'm crazy. As it turned out, he was eligible with significant delays in language, cognitive and fine motor skills.

He started the special education program, and things went relatively well for the first 6 months as Kieren's language started to emerge and he became a little more in control of his actions. I will never forget the first home visit I had with the special education teacher. She told me how Kieren didn't do this or that, wouldn't pay attention, kept flapping his hands, and wouldn't sit down and eat (tell me something I don't know!). During that visit I could hardly talk for fear of crying. I felt she was telling me what a lousy job I had done in bringing up my son. I blamed myself for a long time, thinking I should



"A Parent's Perspective"

have done something and he would be normal. I thought that the "experts" knew what they were talking about, and I tended to listen more to them than to my inner feelings.

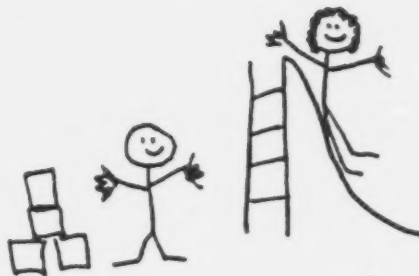
I am glad to say that now I know better. I listen to myself first, and then incorporate what the "experts" say into my plan. I've learned the hard way that parents are the experts on their child, and what's good for one child is not necessarily so for all children.

— Itala Eller, 1997, *Parent*

Malachi

I have a special sibling. My brother is intelligent and trusting and 2 1/2 years older than me. When we were little, we used to have bitter sock wars on laundry day, and he taught me all about dinosaurs (he knew a lot about dinosaurs). He drew these amazing, elaborate, creative pictures. I remember one called "War of the Grapes." It was a crayon picture of hundreds of little grapes in all kinds of armor and camouflage, and the red grapes were battling the green grapes. You looked at this picture and were amazed at the 7-year-old mind that constructed it.

Malachi also has a disability. For many years, my parents have been trying to figure out what disability it is. His symptoms have grown progressively worse since he was young, although,



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"Malachi"

at times, some medications have given us hope for improvement. Malachi is painfully shy. While he learned to make eye contact, you wish he would stop, it seems so painful for him. To ask him a question, you need to get his attention, then repeat the question until he understands, and wait patiently for his answer. Malachi never asks the follow-up questions to statements, and he rarely involves himself in a conversation involving more than one person. He has trouble with directions. While he nods and indicates that he understands, he may not recall the conversation when it is time to carry the directions out. Malachi was slow to speak, and used a speech therapist for a time after he learned his first words.

Later, Malachi started talking to himself, repeating the same words over and over while he worked them out in his complicated brain. When he was a teenager, he started talking more roughly to himself, pounding his fist in the wall, having even more trouble focusing. His counselors don't know how to label him. At different times, he has been diagnosed with learning disabilities, speech delays, a perceptual disorder, pervasive developmental disorder, brain injury, mild mental retardation, depression, schizophrenia, and disassociative disorder. He doesn't fit into a neat little box. But who does? At this point, I give up. My parents, still trying to find services to help him and guidance for their work with him, need a diagnosis. Otherwise, how will he be eligible? How will they know what interventions to try next?



"Malachi"

When we were little, there was special education for Malachi, but he was intelligent, with no physical disabilities. The services offered to him were very limited. There was certainly no respite. When I turned 6, I entered public school with Malachi. My parents had recently gotten divorced, and my mother had to work, but she could not afford any of the child care options available to us.

We became "latchkey children." Malachi and I always came home right after school. Malachi always met me at home, and he went in first to check the closets and the basement for monsters and kidnapers. Together, Malachi and I did our homework and the chores that Mom laid out for us the night before. I am sure that, when Malachi thinks about that time, he remembers me as bossy. We bickered A LOT. (Imagine that! Siblings bickering?) We wanted to make sure that Mom would be in a good mood when she came home, and I knew that Malachi needed to be told to do things more than once in order to make sure that they got done.

When Malachi started experiencing new symptoms, I was starting high school, and I was given the opportunity to tune out. I got VERY involved in school activities and spent little time at home. My mother, exhausted by Malachi's constant needs and frustrated because she still did not know what was going on with him, just could no longer have him in the home. Malachi moved to my Dad's. For many years afterwards, I did not really know him or the

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"A Sibling's Perspective"

person that he became. Maybe if my life with him had not been so intense when we were younger, I would have stayed connected with him during that time. My respite in high school was WONDERFUL for me, but it came too late in my relationship with Malachi. As I work to reestablish my relationship with him, I have a lot of regret. I can look back and say that respite would have been very important to us all at a crucial time in our lives.

So, in Malachi, I have a special sibling. I never had a brother who screened my dates or scared off my bullies or who my friends had crushes on when I was younger. When my parents divorced, I never talked to Malachi about my anger, and he will not celebrate my wedding day the way that I always felt a brother should. We might never have a deep meaningful conversation about our life paths. I will always miss all those things with him. But Malachi is one of the greatest teachers I ever had, and, these days, I am learning to enjoy all of the things we are able to do together and appreciate all of the things that he is. He is a very special sibling.

— *Anonymous, 1997, Sibling*

A Sibling Perspective

My brother David Eugene Ownby was born with multiple disabilities—profound mental retardation, epilepsy, cerebral palsy, and microcephaly. I was 3 years old when my parents brought him home from



"A Sibling's Perspective"

the hospital. They gave me a life-size doll that day -- but I wanted the real baby. I always took my responsibility of being the big sister seriously. I made sure that I "protected" David. When other kids made fun of him, they quickly got an education in disability awareness. I made sure they knew that David had feelings just like the rest of us. Although he could not talk, he still knew when someone was making fun of him. Little did I know I was becoming an advocate.

David required a significant level of care. Both my parents worked, and, while most any babysitter would watch me, few wanted to watch David. My parents tried many variations of baby-sitters, from live-in nannies to next-door neighbors. Most often sitters would watch me and David for a week or two and then David would have a grand mal seizure. That coupled with the rush to the emergency room would usually result in the sitter agreeing to watch only me and not David.

Respite was not an option for my family in the early seventies. While my family worked with many therapists and social workers, the only options given to them were permanent foster care or institutionalization for David. Neither sounded very appealing, but my parents' ability to function as a family was severely compromised by the time David was 5 years old. My parents needed a break from the demands of caring for David. They approached the social workers about institutionalization. A



"A Sibling's Perspective"

"state of the art" institution had just been built 8 miles from our home. This service was touted as the best option available. Even still, the waiting lists were long, and David was denied admission time and time again. My father knew Senator Hubert Humphrey and, with his political clout, my parents did what they thought was the best thing for David and my family -- institutionalized David.

While having David cared for on a daily basis by caregivers in the institution was a relief, my family quickly learned that institutional life was not conducive to normalization -- it was not a home. My mom quit her job at the Library of Congress to manage the institution's library and be close to David. I quickly became involved with Special Olympics and volunteered there most Saturdays. My family and I stayed actively involved in David's life, bringing him home on the weekends and visiting often during the week. While this seemed to work for our family, I always felt that David was cheated. I did not think it was fair that he had to live there. I vowed at age 7 to "grow up" and change things for people like my brother.

I had to wait until I was 18 years old to become employed at the institution where David lived, and, when I did, I got a job there. I wanted to know what went on behind closed doors. While my mom had some sense of institutional life, she was far removed from the living units and day-to-day activities. I was employed as a direct care aide. I quickly learned



"A Sibling's Perspective"

what I had always felt -- institutional life should not be an option for people like David. This environment was volatile, violent, uncaring, and stripped residents of their basic human dignity. As a young adult, I vowed to find David a better living situation. I wanted to become a disability rights advocate and work to change the system, allowing real choice for families and people with disabilities.

In seeking services for David, I faced what so many families still face -- closed doors, long waiting lists, and lack of services. The care David received at the institution was never good enough for me and had gotten considerably worse. More frequently, my parents and I met David at the emergency room with unexplained broken bones, bumps, and bruises.

In May 1992 David was left unattended in his institution bedroom after a series of grand mal seizures and aspirated. When institution aides found him, he was unconscious, with no respiration or pulse, and was cyanotic. He was rushed to the hospital and lived on life support for 2 months.

David had taught me long ago to never give up. He was certainly a fighter. He always bounced back from an injury or illness, and there were so many -- we all thought for sure he'd live through this too. While David struggled to live, this fight was too hard. In the time he had been left unconscious, he suffered significant brain damage. He was now blind, paralyzed, unable to swallow, and all the large

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"Caregiver's Perspective"

organs in his body had begun to atrophy. My little brother was dying and my advocacy was too late.

David did die, but not in vain. While my efforts to help him move into a group home failed him, his death, my advocacy, and many others' resulted in 80 other residents having the real choice to live in a home. While I advocated to close this institution, after 5 years it remains open, but considerably smaller, better staffed, and closely watched by agencies providing oversight.

I learned from David to laugh, to have fun with the little things in life, and to persevere. I held David's hand as he lay dying and promised him I would work to ensure that no one else would have to suffer this way and that I would commit my life to making real choices for families and people with disabilities. I promised to share his story and make sure as many people as possible knew him. While David and I can no longer do McDonalds on a Saturday afternoon, and I'll never again have a big bear hug from him, he is alive in the work that I do. His life has given me my perspective.

— Lisa Ownby, 1997, *Sibling*

One Caregiver's Perspective

Respite caregiving for children with disabilities and their families truly presents an opportunity for a "give and take" relationship. This has been my experience from the time I decided to attend group

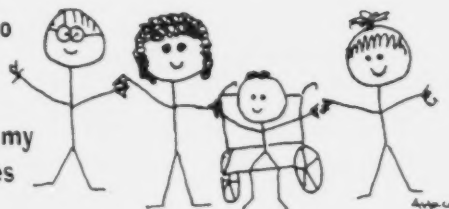


"Caregiver's Perspective"

training, through working as group caregiver, and finally when a family "match" occurred.

My initial interest in respite was both personal and professional in nature. Being a single person without children left me feeling the need for contact with children, and my work in the social/health care field made working with children with disabilities a natural. I truly felt that I had personal traits of an affinity for children, patience, and a desire to learn and help a family. At that point, I signed up for training without knowing the specifics. What an informative, supportive, friendly, and nonthreatening experience!

Following initial training, small group exposure to children and the opportunity to discuss the children's needs and personalities with their families gradually increased my confidence and my joy in understanding that children with disabilities appreciate interest, hugs, snacks, toys, walks, playing ball, swings and slides as well! Challenges are there too! They may come in the way of feeding, behavior challenges, toileting, or special wheelchair accommodations, which may initially be unfamiliar to caregivers.



This is where the "give and take" occurs on the part of caregivers and families. Caregivers need training, feedback, and encouragement from the family "experts" in order to best understand the child's limits and special needs. Caregivers may appear to ask many questions, seem anxious, and

"Caregiver's Perspective"

anticipate what to do in an emergency. I believe families can aid caregivers by remembering their own initial thoughts and feelings about helping their child with his/her limitations. On the other hand, caregivers may want to appear knowledgeable and confident and not ask too many questions! Families, please anticipate this and **VOLUNTEER INFORMATION!**

My caregiving experience with a 9 year old and his 6-year-old brother has truly been rewarding and fun! This match occurred following group respite in which I had the chance to interact, observe, and build a relationship with both brothers and parents. A need for individual respite was there, and I had the time and geographic availability. Truly a match made in heaven! I really feel that this family provided information, training, and demonstration about their son's needs. I had the opportunity to question, observe, and build a relationship with the parents as well. I believe that caregivers need to maintain contact periodically in between respite dates to develop rapport. This also helps families feel freer to call upon the caregiver, particularly families that typically "do it all" or have difficulty in asking for help. Families and caregivers need to communicate and appreciate the gifts each has to bring to this partnership. The Partners Plus program is truly partners in action!

— *Linda Malone, 1997, Caregiver*



Stress, Special Challenges

Stress

The potential for stress exists in all of our lives. Stress may be good or positive stress (eustress), or bad or negative (distress). The key to coping with stress depends on how you perceive a situation or life event. Stress is also closely related to your view of how hard or easy it may be to manage the event. For example, going on vacation can be perceived as both good and not so good. Many of us welcome vacations! Yet, vacations may be a major source of stress if you consider the packing, the drive, making reservations, or scheduling time to be difficult. Many strategies are available to both families and caregivers to help cope with daily stress. Included in the following pages are things families and caregivers can do to reduce stress, prevent *burn out*, and ensure successful respite relationships.

The Special Challenges of Parenting

Being a parent involves many changes, which may be perceived as stressful. Families who have children with special needs share the stresses of all families facing the challenges of parenting. In addition, they may have other challenges related to their children's special health, education, and care needs. Many resources are available to help families cope with these special challenges.



Learning to Cope

The Special Challenges of Caregiving

Being a caregiver for children with special needs can be stressful too. Caregivers are responsible for the children in their care. If those children need extra attention or medical care, caregivers are more challenged. In addition, it takes time to become comfortable with children and familiar with their needs and strengths. Not knowing what to expect from children can be stressful. Caregivers who are still learning about the children in their care may experience stress.

Coping with Stress

If you perceive a situation as stressful or hard to manage, you can reduce your stress by using a variety of coping strategies. Consider some ways you deal with stressful situations or special challenges. You might already know strategies that work well for you. For example, it might help to talk with family and friends in hard times.

Families often use respite to cope with stress. Taking a break from daily demands not only is relaxing, it allows families time to try the strategies listed on the following page. Families may want to talk with caregivers about how they use respite time to cope with stress.

Caregivers may need specific ways to cope with the challenges of working with children with special needs. Caregivers and families need to take time to talk after respite takes place. Was there anything that was stressful? Is there more information families can share? Are there



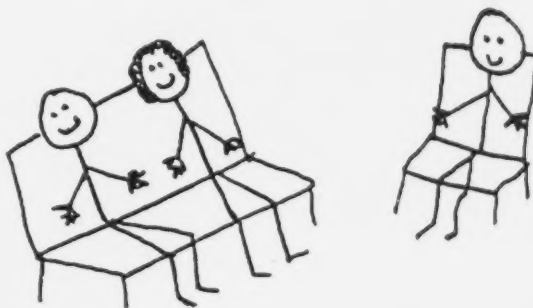
Dealing with Stress

new skills the caregiver can learn? Certain caregivers may want soothing music playing as they work with your child(ren) or use other methods to create a calm atmosphere. Families can encourage caregivers to talk about how they handle stress. Together, caregivers and families can work out ways for caregivers to relieve stress during respite. The following fact sheet lists strategies you may find useful in reducing your stress.

Strategies for Dealing with Stress

People deal with stress in many ways. Here are some examples:

- Seeking information
- Sharing information
- Learning new skills
- Doing something that makes them laugh
- Listening to something they find soothing
- Planning ahead
- Finding a favorite cartoon that brings a smile to their face
- Walking, jogging, hiking, swimming, playing
- Communicating openly
- Taking a break



Challenges of Respite

The Challenges of Respite

Building effective partnerships takes time and skill. Families and caregivers need to know how to work together for successful respite care.

One problem families often face is keeping caregivers. Families tell us many respite caregivers cancel appointments. We also know that many caregivers stop providing respite. Respite caregivers cancel or quit for many reasons. Why do you think they quit? The information in this section will help you understand why and help you develop strategies to build successful respite partnerships.

Caregivers may stop giving respite for the following reasons:

- **Respite is harder than they expect.**
- **Time demands are too great.**
- **Physical demands are too great.**
- ***Burnout* occurs.**
- **Training was not adequate.**
- **Patience wears out.**
- **They don't feel appreciated.**
- **They are not paid enough.**



Meeting the Challenge

Meeting the Challenge

Taking these steps can help you meet the challenge of respite:

- Understand the family's purpose for respite.
- Work with the family to develop a thorough training plan.
- Discuss a schedule for providing care.
- Avoid overcommitting your time and energy.
- Be clear about your terms for providing respite.
- Learn more about working with families.
- Talk to other caregivers to share ideas and support.

More Things to Know About Families with Children with Special Needs

- Individual families have their own values, beliefs, customs, and courtesies, and what is most important to one family may not be to another.
- Sometimes families have fears and bad feelings about their children's disabilities.
- Families with children with special needs generally have the same kinds of daily routines as other families.
- Families with children with special needs have to learn more about how to help their children.

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How You Can Help Families

- Children with special needs like to play and have fun.
- Children with special needs and their families can help others learn new things, like sign language.
- Children with special needs grow and develop with love and support from their families and others.
- Children with special needs and their families want to be accepted by others.
- Families wonder if their children with disabilities can do things that other children do.
- Families hope there will be services to help them and their children at school and in the community.
- Families have information about their children's special needs to share with caregivers.
- Families need others to know that it is okay to have children with disabilities.

How You Can Help Families

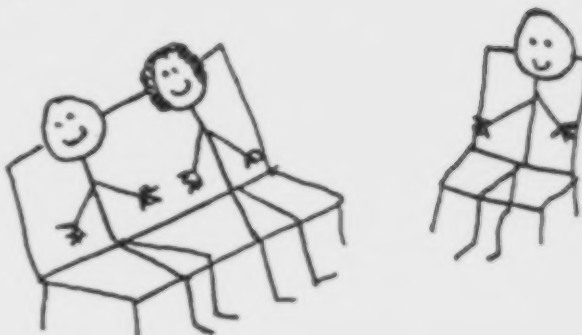
Remember that families and caregivers bring unique backgrounds and experiences to the respite caregiving partnership. Some ways to show respect to a family are being on time, keeping an appointment, and keeping scheduled times and dates to provide care.



Building Successful Partnerships

There are also other ways that you can help families:

- Be supportive.
- Communicate honestly and openly.
- Ask questions.
- Be an advocate for them.
- Help recruit other caregivers.
- Be dependable.



Successful Family and Caregiver Partnerships

Families and caregivers can build successful partnerships by doing these things:

- Appreciate differences in skills and approach.
- Be willing to learn from each other.
- Ask each other for help.
- Allow time to talk with each other.
- Share experiences.
- Be willing to work together, even when differences occur.
- Be flexible in trying new ways.
- Have a sense of humor and fun.
- Be patient when things are not clear or exact.
- Share commitment to children with special needs.

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Section 4

All Kids Like Cookies
activity

All Kids Like Cookies

All Kids Like Cookies

Children with special needs are important members of respite partnerships. The following activity is designed to allow you the opportunity to experience some of the daily challenges children with special needs face. This may be useful in understanding a child's perspective and keeping that in mind when developing respite partnerships.



We know children with special needs are more similar to other children than different. "All Kids Like Cookies" is a series of activities designed to help persons without special needs experience challenges children with special needs face every day. You can do the activities on the next pages by yourself or with a group. Answer the questions at the end of each page as you finish each activity. This will help you become more aware of what it is like to have special needs. As you will see, from the perspective of the child with special needs, the world is a more challenging place.

We cannot help until we understand.

We cannot understand until we feel.

We cannot feel until we become.

(Council for Exceptional Children)

Adapted from:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *SpecialCare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.

Activity Sheet

All Kids Like Cookies Activity Sheet

The following activities can be done alone or with a group. During the activities you remain yourself, but a special challenge is added. Think about how you feel when doing each of these activities and be aware of any adaptation you make.

To experience a visual impairment, you will need:

- a blindfold
- a pitcher of water
- an empty glass
- a crayon or other marker
- a page out of a coloring book or a crossword puzzle
- a child's storybook or magazine

- Put a strip of cloth over your eyes and tie it around your head to make a blindfold.
- Pour water from the pitcher into the glass.
- Color the coloring book page or complete the crossword puzzle.
- Read the storybook or magazine.

Questions

- How did you hold your head while pouring water, coloring, and reading?
- If doing this activity with a group, did anyone talk you through the tasks?



Activity Sheet

- What other senses did you use to help yourself? (touch, sound, smell)
- Did it matter that you were coloring out of the lines or what color you were using?
- Were you able to complete the crossword puzzle?

Vision helps a child learn about the objects and people in the world around them. Few children are totally blind. A child is considered to have a visual impairment if the child's ability to see after correction limits his ability to learn through vision.



To experience a speech and language impairment, you will need:

a bag of large marshmallows and gauze
one other person or a small group

- Put enough marshmallows or gauze in your mouth to fill it; two or three usually work.
- Say your name and give your address or phone number.
- Ask your partner or others in the group to bring you something.
- Tell your partner or others something you did today.



Activity Sheet

Questions

- How were your words spoken differently?
- How did you feel when others did not understand you?
- If you spoke this way all the time and others laughed at you, would you want to talk very much?

Sometimes children with speech and language impairments stop talking rather than cope with the difficulty of getting people to understand them.

To experience a physical disability that affects using the smaller muscles in your body, like the ones in your fingers, you will need:

a pair of large garden or work gloves
a puzzle
a string and macaroni with holes or beads
very small toys that have moveable parts

- Put the gloves on.
- String the macaroni or beads.
- Put the puzzle together.
- Play with the toy.
- If you are wearing a watch, take it off and put it back on.
- If you are wearing earrings, take them out and put them back in.



Activity Sheet

Questions

- Were you able to pick things up easily?
- Did you need more time to put the puzzle together?
- Were you able to put on your watch and/or earrings?

To experience a physical impairment that affects the large muscles of the body (like the ones you use for walking) you will need:

a kick ball

a large toy like a stuffed animal or truck

a video

- Place the ball between your ankles and keep your hands folded together.
- Walk 10 feet with the ball between your ankles and pick up the toy or video.
- If doing this with a group, hand the toy or video to someone else.

Questions

- Did you take a long time to get to the toy or video?
- Did you feel awkward?
- Did you drop anything?

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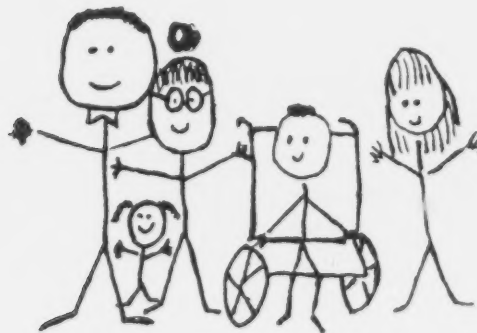
Activity Sheet

Children first learn to explore their surroundings by using their large muscles to move around. Children learn how things work by using the small muscles of their hands to explore toys.

Children delayed in their motor development have difficulty learning to become physically independent because they cannot move well. Children with small muscle development delays may have difficulty feeding and dressing themselves or learning how things work because they cannot use their hands and fingers well.

Source:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *SpecialCare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.



Notes on this Section

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Section 5

disabilities

awareness

Understanding Disabilities

Understanding Disabilities

The purpose of this section is to increase your knowledge and awareness of the terms, services, and issues related to disability services. This section contains many ideas, words, and issues that may be new to you, although these are everyday concepts for families of children with special needs.

For parents of a child with special needs, every day becomes a day of learning. Parents may learn how to adapt a cup so their child can learn to take a drink. A parent may learn about a new treatment procedure from a family doctor. Parents may also learn more about the educational system and its services and about the many words and acronyms used by professionals who work with their children. As a caregiver, you will be able to learn from Partners plus training and from the families of children in your care.

Included is a summary of the educational services that are available to children with special needs and the terms and abbreviations that are often used. As you learn more from group and personalized training, you will begin to understand some challenges that families face. Through understanding, we can all work together to help others in our community become aware of the issues affecting children with special needs and their families.

Children first learn to explore their surroundings by using their large muscles to move around. Children learn how things work by using the small muscles of their hands to explore toys. Children delayed in their motor development

A Few Words from Families

Family perspectives have been included throughout this section. While there are many policies and guidelines that explain educational services for children with special needs, a family's experience can be very different from what is expected or written.

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Finding Educational Services

have difficulty learning to become physically independent because they cannot move well. Children with small muscle development delays may have difficulty feeding and dressing themselves or learning how things work because they cannot use their hands and fingers well.

Source:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *SpecialCare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.

Educational Services

- Federal legislation called IDEA (Individuals with Disabilities Education Act) is now in place to make sure that children with disabilities receive special services. Infants and toddlers with disabilities (ages birth through 2) may receive early intervention services. The public schools provide children from 3 to 21 a free and appropriate public education. For preschool children (ages 3 to 5), services are called early childhood special education (ECSE) services. Older children receive special education services. Beyond school, families and individuals with disabilities rely on residential and vocational support services from both public and private providers.



Finding Educational Services

- Children who receive special services will have an individual plan written for them each year. For children under age 3 in early intervention services, the plan is usually called the Individualized Family Service Plan, or IFSP. In special education services, the plan is usually called the Individualized Education Program, or IEP. In residential and vocational services, it is usually called the Individualized Service Plan (ISP) or Individualized Transition Plan (ITP).
- The IFSP, the IEP, the ISP, and the ITP all include goals for each child, information about the child's development, and activities to be used to help the child reach his individual goals. Ask the family if they will share their child's plan with you so that you will know more about the child's development and how you can help. Because an IFSP includes a plan for the family, it may be personal and you may want to ask families to share the child portion of their IFSP only.
- A plan must be developed by a team that includes members of a child's family. Team membership varies and may include people such as a special educator, a speech pathologist, an occupational therapist, a physical therapist, a nurse, or others.
- Your observations and ideas about the child's activities during respite are important for the family to have when they help develop their child's plan.



Understanding Early Intervention

What Is Early Intervention?

Early intervention is a system of services for young children, birth through 2 years of age, and their families. It is designed for children who have disabilities or a delay in development and, in some states, for children who are at-risk for developmental delay. In early intervention, parents and professionals work together as partners. Each brings important information and skills to the partnership.

The agency responsible for early intervention is different in each state, and early intervention services are provided by many different agencies, programs, and professionals in each community. If a child is eligible for early intervention in your state, federal and state policies help to ensure that each family gets the services they want and need.

Adapted from:

Allport, C. (1991). *A guide to early intervention: A resource for families*. Lightfoot, VA: Child Development Resources.

*"Our dream has
become a simple
one . . . for Becky to
experience life as
other kids do, and
for her to be happy."*

Why Are There Programs and Services for Infants, Toddlers, and Their Families?

- Working with some babies early in life helps to prevent later problems in their development.



Understanding Early Intervention

- Experience and research has shown that working with children with disabilities early in life helps reduce the effects of their disabilities.
- Early intervention programs and services help families with concerns they have for their children with special needs or disabilities.
- Although many children learn to crawl, talk, and play without much help, some children need special help. Early intervention can help families become more skilled at encouraging the development of children with special needs.
- Early intervention programs and services can help families learn more about child growth and development and how to manage children's behavior.

Adapted from:

Allport, C. (1991). *A guide to early intervention: A resource for families*. Lightfoot, VA: Child Development Resources.

The following are firsthand stories from families to help you learn a little more about disability services.



"Our Family Journey"

"Our Family Journey in Early Intervention"

Matthew was born with chromosomal anomalies that affected every cell in his body. The doctors prescribed his prognosis as quite grim. His medical and developmental problems were so pervasive that his life span was predicted to be short and his quality of life poor. During the 3 years of our son's life, he did not grow beyond 5 pounds and did not develop beyond infancy.

Our son's needs and our family's needs were not well matched to the more traditional kinds of early intervention services. Since our family had decided early on to care for Matthew in our home and to pursue a family lifestyle as close to the way we saw other typical families, we needed an early intervention service that would help us meet these goals. Early intervention helped our family by providing services like respite care through a center-based play group.

Another service I found helpful was the parents' group where I received a lot of support from other families with children with disabilities. Other parents and the staff of the early intervention program helped me find ways to cope with the everyday stresses of caring for a chronically ill child and still be a "mom" to my other child. Through their help and special friends in the community, I could continue to enjoy life for myself and with others. Professionals helped me and my husband understand the medical implications of caring for our son so that we could keep Matthew at home. Physical and occupational therapists helped show us



"Jack's Story"

ways to keep Matthew as healthy and comfortable as possible. The greatest help given to us by early interventionists was in sharing with us information about our son's disability and in encouraging us as a family. We gained the confidence we needed to live with and care for our medically fragile child.

— Dee Moore, 1997, Parent

"Jack's Story"

Jack was born 8 to 10 weeks premature, and it was over a year before doctors would agree to tests to confirm my suspicions that Jack was more than just premature. After a battery of tests, he was diagnosed with spastic quadriplegic cerebral palsy with a chance of mild to severe mental retardation. Those words changed our lives forever, first accepting the diagnosis and then striving to do the best for our son.



One of the best things we learned as parents is that what we feel and have been advised for Jack is best is not necessarily what the school system deems to be required. But having said that, I will say that the early years in the school system were much easier than the later years have been. Jack's needs were met in ways that were beneficial to me as a parent as well as Jack. I learned a great deal from his teacher and his physical, occupational, and speech therapists, ideas that were carried over to the home to provide continuity.

Jack's elementary school years were spent in a segregated classroom. There were no typically-



"Jack's Story"

developing kids in this classroom; only kids with special needs. By the time Jack entered school, he was classified not only as orthopedically handicapped, but also as visually impaired and learning disabled. He had a severe startle reflex and did his best work in a one-on-one setting. With Jack's teacher and therapists, we tried many ways of teaching Jack and found that he could orally comprehend at a much higher level than he could read. By properly using his IEP, we could plan for Jack individual needs and how best to meet them.

Later, Jack was placed into some regular classes (with typically-developing kids) with a full-time aide. The aide allowed Jack to work on his independent goals without taking away instructional time from other students. Being in regular classes allowed Jack to be with a wider variety of people, increase his social skills, better his self-esteem, and generally feel more a part of the school. His IEP has allowed refinements over the years to accommodate Jack's abilities such as auditory learning skills and providing for his tests to be taken orally with the help of his aide. However, IEPs often look good on paper but are not always followed in practice.

We have learned there are several important things that can be done to benefit Jack in the school system. First, know his rights and our rights as parents in the educational process. Families are a child's best advocate and at times may be the only advocate. Second, parents have to be knowledgeable of their child's needs and what must be done to meet those needs. Third, there are public and private organizations and advocates who are willing to help, often at no charge to the family. They provide support, knowledge,



"Thoughts on Special Education"

and backing needed to make a child's rights known. School systems have, in many cases, become more concerned with the monetary bottom line and often do not provide information about a child's rights and entitlements.

Our most negative experiences have been with those teachers and other personnel who see our son not as a student but as "handicapped." In those cases where teachers and others care and have the desire and ability to accept Jack as a student, and then figure out ways to accommodate his needs, a great deal more progress has been made with a lot less effort.

— Susan Bohannon, 1997, Parent

"A Parent's Thoughts on Special Education"

In addition to special education, my son also receives physical therapy from a certified therapist, and he receives vision services since he is also visually impaired. Unfortunately, my son, and often other children as well, does not receive the amount of therapy recommended by a therapist because schools have limited budgets and must serve many children. However, I have found my son's teacher to be extraordinary. She is very helpful in getting information to parents. This is true of the parent resource person also. Parents share information and resources with each other as well. Unfortunately, I have found that often I must be an active advocate to ensure my son receives the services he needs. Equipment is often hard to get and acceptance by some regular education teachers and other students can be hard to come by. The IEP process can help

Common Issues for Families

families get the services their child needs, but in the beginning it can be intimidating. I have learned that the IEP is very important to my son's education.

— Teresa Lewis, 1997, Parent

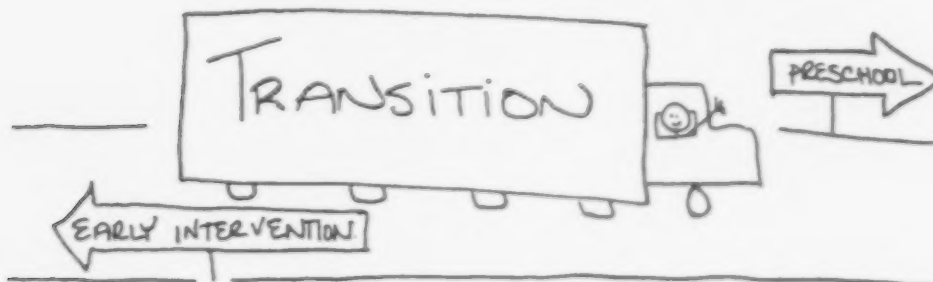
Common Issues Families Face

The following are some common issues facing people with disabilities and their families.

Transition

For families who have children with special needs, life is full of transitions. From the time these families bring their children home from the hospital, many are involved in a service system designed to help support the family and meet the needs of the child. Families are initially involved in the early intervention system. Then they may make a transition to early childhood education and then on to special education, and ultimately they may tap into vocational and residential supports for the child.

Once in the school system, children will move from elementary,



"A Parent's Perspective on Transition"

to middle, and then to high school. While all families who have children will experience these transitions, for families who have children with special needs, this means not only new schools but new therapists, new social workers, new nurses, a new Individualized Education Program (IEP), etc. These families must constantly learn new systems of support. In some respects it makes getting services for their children very difficult, because each system is so different. So, often when a family feels like they finally understand one system of support, their child moves on to another, and the process of learning the system starts all over again.

Service systems can be very frustrating for families and their children. Not only do systems change as the child ages, but they differ from locality to locality, from state to state, and around the country. This can be especially difficult for military families and for families who must move a lot due to their jobs.

"A Parent's Perspective on Transition from Preschool to Kindergarten"

When Patrick was born, he seemed normal in every aspect. By the time he was about 18 months old, we realized that something did not seem quite right. He did not talk much, walked a little late, and had almost no interest in people. All his pediatrician said to us was "Do not worry—all children develop a little differently." When Patrick was 2 1/2 years old, we moved to Virginia from New Hampshire. Shortly after we moved, Patrick stopped talking altogether and his temper tantrums were horrible. We kept thinking it had something to do



"A Parent's Perspective on Transition"

with the move, not having other children to play with, or we were doing something wrong. At his 3-year checkup, his pediatrician sent us to specialists. He was tested and observed, and on a rainy day in November, the diagnosis came. "Autism."

We called our local school system to see about early intervention services, and Patrick again went through more testing and observation. After all was done, we were delighted to find out he would be put in a special education preschool class in a local elementary school. We were thrilled! There was somebody out there to help us at a point when we felt as though we were losing ground. Patrick was put in a small class of seven children with a good teacher and a wonderful aide. He adjusted fairly quickly, and we could tell he loved school. Patrick got speech therapy and occupation therapy as part of his special services. In addition to language and other preschool activities, Patrick also worked on things such as potty training, dressing and undressing, how to play with other children, and gross and fine motor skills. We also got home visits from the teacher to discuss problems and concerns and to help us whenever needed.

Recently we had our first real IEP meeting. Patrick is going into kindergarten. Getting ready for the IEP meeting was a little scary. Patrick was going to a new school in an inclusion program. We were dealing with an all new staff. Would they be willing to work with us to get everything our son needed? In preschool, we had gotten to know the school staff and pretty much knew



"A Parent's Perspective on Transition"

what to expect. We were also not sure if we would get all the services we felt Patrick needed. Patrick had also been riding on a small bus with only his peers; next year he will be on a bigger bus with children of different ages.

The IEP meeting went well, although we are somewhat still concerned for his next school year. In preschool he was taught with all developmentally-delayed children, and this would be his first time being taught with nondisabled peers. How will he match up with them? How will they treat him? Will he make friends?

Patrick will have the same speech and occupational therapists, which is at least one constant for him and something he needs. The goals for next year changed also because he will deal more with academics, writing skills, and language, although social skills will still be very important. That was a big concern for us. We were afraid that if Patrick did not have an aide that he would be lost in the shuffle. We are still nervous and have many questions in our heads, but , after meeting the special education teacher and vice principal and going through the IEP, we feel better about the new experience ahead of him. With the help of teachers, aides, and everyone else involved with him, we feel sure that he will do fine.

— *Deborah Warren, 1997, Parent*

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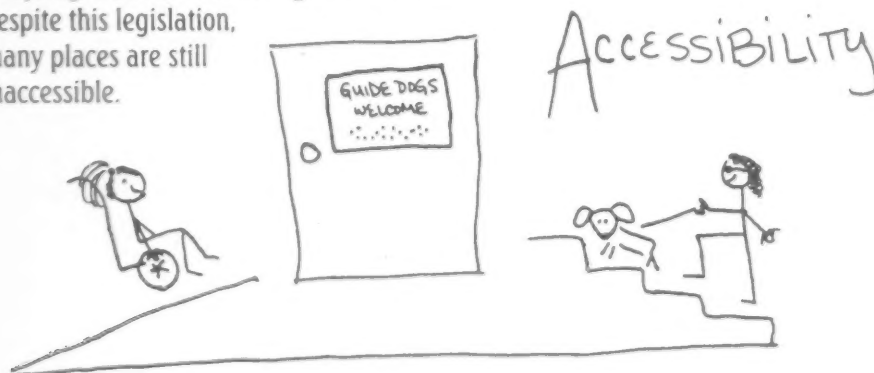


Common Issues for Families

Accessibility

With the passage of the Americans with Disabilities Act (ADA) in 1990, America has made many changes to help make things more accessible for people with disabilities. The ADA requires that public buildings be accessible for people with disabilities. This means there must be curb cuts, elevators, easily usable door handles, timed door openers, braille signage, TDD/TTY (access to phones for the hearing impaired), etc. Likewise, ADA prohibits businesses from forcing people with disabilities to use back entrances. For years, the only way into some buildings was through kitchen or delivery doors. This was demoralizing to people with disabilities. With the ADA, people with disabilities have access through front doors like everyone else.

While the ADA represents progress, many facilities remain inaccessible to people with disabilities. Some buildings, such as religious or historic buildings, are exempt from adapting their facilities. In addition, all buildings have a certain amount of time in which to comply with the ADA. Finally, agencies can get exemptions from the ADA when the costs of adapting facilities are too high. As a result, despite this legislation, many places are still inaccessible.



Common Issues for Families

It is important to appreciate how much forethought persons with a disability or families of children with special needs must make each time they leave their house. They must plan ahead in case they are unable to enter a building, read a sign, hear a presenter, see an overhead, roll off the curb, open a door, etc.

As mentioned earlier, accessibility means more than wider doorways and ramps. Accessibility is also about stigma. Even with the ADA, our society is not always comfortable with disability and this is often reflected in the words people use, in uncomfortable silences, and in unnerving stares. So, often, even when a building is accessible, the people inside are not welcoming. This is very discouraging for people with disabilities and their families.

One thing that a parent of a child with disabilities desires most is for their child to develop friendships with other children of the same age. It is difficult for this to happen unless children have an opportunity to be together. Enrollment in a program is not enough. Once enrolled, the child must have access to the activities going on in the child care setting. Interaction occurs when caregivers have arranged an environment that sends the message to children that says "this is a place for me."

A good way to think about accessibility is to arrange the setting so that anyone can see that it is a place that includes all children in play, learning, and recreational activities. Accessible environments should have play materials and equipment that are seeable, reachable, and usable for all children. A setting that offers a warm welcome to all who wish to use it is accessible.

Adapted from:

Osborne, S., Kniest, B.,
Garland, C., Moore, D.,
and Usry, D. (1993).
*Specialcare curriculum
and trainer's manual.*
Lightfoot, VA: Child
Development Resources.

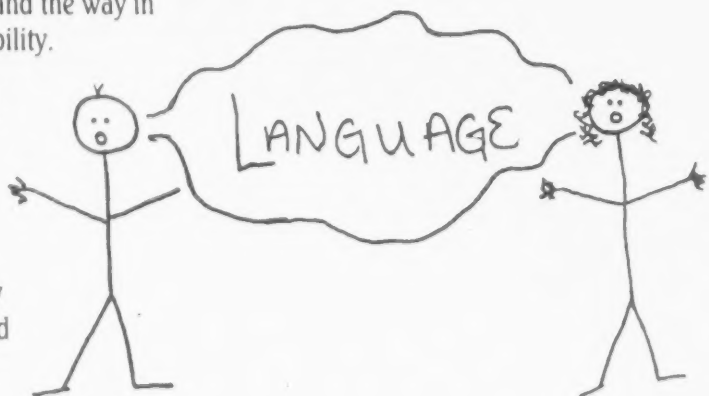
Common Issues for Families

Language

People with disabilities and their families are sensitive to the language we use to refer to disabilities. It is helpful and respectful to use people-first language. This is a way of speaking that mentions the person before the disability. A person may be referred to as *the blind child* or *epileptic man*. Using people-first language, you would say *the child who is blind* or *the man who has epilepsy*. This way of speaking makes it clear that the disability does not define who the person is but is one important characteristic.

People with disabilities across the country have expressed their preferences about the words that we use to describe their special needs. Besides using people-first language, the word *disability* is preferred over the word *handicapped*. The term *special needs* is often used to describe children with a range of disabilities, developmental delays, and/or special health care needs. Over the years, people with and without disabilities have changed the words and the way in which we talk about disability.

Years ago you may have heard someone described as *wheelchair bound*, *crippled*, *challenged*, *stricken with* . . . These words are no longer preferred by the disability community. Language and words we use change with time.



How Parents Describe Their Child

Because language changes, it is important as a caregiver to always use people-first language *and to listen to the words that families use*. Those are the words that you should use when talking with them about their child. For example, parents of older children or adults with disabilities may refer to their child as *handicapped*, because that was the word used many years ago and they may still be comfortable using it. Don't feel like you must correct a family in the words they use. Rather, model people-first language and use the words they use to describe their child.

Describing Children

Parents of children with special needs may choose to describe their children very differently from the ways in which doctors or other professionals would describe their children. Some parents have described their children in the following ways:

- A great kid who loves Barney, Wheel of Fortune, and girls.
- Quiet, handsome, and a bit of a challenge.
- Very happy and expressive. Physical abilities between 6 and 9 months but highly cognitive. Spoiled rotten.
- Calm, cuddly, and easygoing.
- Lovable and easy to care for. Responds to touch and sound. Loves attention, but plays well independently.



How Parents Describe Their Child

- The sweetest, cutest, most adorable child on the face of this earth.
- Good natured and talkative.

It is important to recognize that disability is a natural part of the human experience. Many of us will experience disability in some way, either personally or in our immediate family, in our lifetime. People with disabilities are actively involved in the development of public policy that shapes services and how we think about disability. It's important to be aware of the trends and to listen to the people we support through respite and other services.

Professionals who provide services to people with disabilities and their families create and use many technical terms and abbreviations. This is often a challenge for families to learn. As each child grows and matures, the language changes and a family must learn new words and abbreviations. You can experience the challenge of language through the activities *What Words* and *Alphabet Soup* on the following pages.



What Words Activity

What Words Activity

Language is very powerful, and we as caregivers must be sensitive to families. Words like *retard* and *pitiful crippled boy* are very hurtful and condescending.

Instead of ...

Use ...

Handicapped girl

Retard

Crip

Wheelchair bound

Blind boy

Autistic child



Alphabet Soup Activity

Alphabet Soup

As you continue your training and begin working with families, you may hear new words or letter combinations regarding children with special needs, services, and or other support for children and their families.

Use this worksheet to write down the new words and acronyms that you learn. Remember that we are all learning together, so share your new knowledge with others.

IFSP	Individualized Family Service Plan
IEP	Individualized Education Program



Some Closing Thoughts

Summary

As a respite caregiver you will have an opportunity to meet and work with some wonderful families and their children. In so doing, you will learn about a child, his or her family, and disability awareness. You may even experience part of the stigma associated with disability. You can help with disability awareness by sharing with your friends and family what you have learned and continue to learn from families. It is most important for society to know and recognize that children with special needs are children first. You can be an advocate for families and children everywhere by increasing others' awareness of the issues affecting people with disabilities.

Remember that, while children with special needs are given labels and diagnoses in order to obtain needed services, they are children first who are loved very much by their families.



6

Section 6

understanding

child development

Planning Appropriate Experiences

Understanding Child Development

Providing respite care for children with special needs is not so unlike providing care for typically developing children. Respite caregivers who work with children who have special needs do require some special skills and information to do their jobs effectively. However, the most important knowledge in caring for children is understanding child development.

Plan Appropriate Experiences for Children

We need to understand the order in which we can expect to see different skills develop in children so that we know what children can be expected to learn.

Example:

A very young child first plays alone. Next we expect a child to play with toys close to other children, before being ready to join in play with one or more children.

When we know the range and sequence of typical development, we are able to know what skills we can help a child learn with success and what activities to plan.

Adapted from:

Osborne, S., Kniest, B.,
Garland, C., Moore, D.,
and Usry, D. (1993).
*Specialcare curriculum
and trainer's manual.*
Lightfoot, VA: Child
Development Resources.



Use the Child's Strengths

Plan Activities That Give Children with Disabilities a Chance to Use Their Developmental Strengths.

Many children with disabilities have some areas of development in which their skills are similar to those of their peers. Emphasizing those strengths is important to each child's confidence and overall development.

Example:

A 4-year-old child with mental retardation may not be able to play with others or take part in social activities typical for children her age. However, the way she uses her body may be typical. She can climb on play equipment, ride a trike, and run and jump like other children her age. Giving her opportunities to practice using her muscles will help her to continue developing her abilities, help her to feel good about herself, and give her ways to play with other children. You can help her expand her social skills by building on her strengths, playing near or with other children on playground equipment.

Another Example:

In games where groups of school-aged children participate, caregivers can find opportunities for children with disabilities to take the lead and demonstrate their abilities among peers.



Areas of Development

In games where groups of school aged children participate, caregivers can find opportunities for children with disabilities to take the lead and show their abilities among peers. A child with visual impairment whose motor skills are like that of their peers could take the lead in a game of pinata. In this game, a brightly colored ornament is suspended above children's heads, and blindfolded players take turns hitting it with a stick to break it open. Taking the lead in this game helps the child gain confidence and build self-esteem.

***A Knowledge of Child Development
Will Help You Care for All Children.***

Areas of Development

Child development is an orderly sequence of physical, intellectual, and emotional change that occurs throughout childhood. Although a child develops as a whole person, different words and categories are used to describe different areas of development.

For a child with a disability, understanding the different areas of child development will help us understand the child's development. However, a disability in one or more areas of development frequently affects other areas of development as well.

Adapted from:

Osborne, S., Kniest, B.,
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Usry, D. (1993).
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Areas of Development

Physical Development

Physical development includes gross motor, fine motor, vision, and hearing.

- **Gross motor** refers to how children use their large muscles for activities like sitting, crawling, walking, and climbing.
- **Fine motor** refers to how children use their small muscles for activities such as grasping objects, coloring, turning knobs, chewing, and swallowing.
- **Vision** refers to how children are able to see. A child may have a narrow view of things or may see blurred shapes.
- **Hearing** refers to children's ability to perceive sounds. Do they hear muffled sounds or high or low pitches?

Communication Development

Communication development describes how children let us know what they want, need, or understand.

- **Expressive language** describes how children communicate by using sounds, words, gestures, or communication devices.
- **Receptive language** describes how children understand messages from others.
- **Cognitive development** refers to the ways in which children think, understand the objects

Adapted from:

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Garland, C., Moore, D., &
Usry, D. (1993).

*Specialcare curriculum
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Development Resources.



Basics of Child Development

and experiences in their environments, and solve problems.

- **Adaptive development** refers to the ways children take care of their personal needs such as dressing, brushing teeth, and drinking from a cup or bottle.
- **Social or emotional development** refers to the feelings and thoughts that a child has about herself and the people around her.

Young children who do not yet show skills expected at their age in one or more areas of development may be considered to have developmental delay.

Basics of Child Development

There are several principles that describe how development occurs. There are patterns, characteristics, or trends that seem to relate to the growth of most children. These principles apply to the growth of children with and without disabilities.

Adapted from:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *Specialcare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.



Basics of Child Development

Development is sequential

Development is sequential. There are steps in each area of development that occur in a certain order. Sometimes children do skip steps in the sequence, but steps do not get reversed or mixed up.

Sequential steps in the development of motor skills:

1. A newborn develops from head to toe.
2. A baby strengthens her neck muscles to control her head.
3. We see baby on her tummy pushing against the bed strengthening her arms, shoulders, and trunk to lift her chest.
4. On her tummy she pulls her knee up and turns her shoulder and hips to roll over.
5. Using her whole arm, she pulls forward and pushes with her feet to creep along.
6. She will pull her knees and feet up under her, push with her arms, and then move her arms and legs in an alternating motion to crawl.
7. She reaches to hold onto something while pulling up to standing.
8. Standing and holding onto something for balance, she cruises around furniture.
9. Without holding onto anything, she takes her first steps.



Basics of Child Development

One Area of Development Affects Another

One area of development affects another. Growth in one area of development is not separate from that in other areas. A child's natural play and everyday routines can make growth happen in all areas of development at the same time. A child may have a disability in one area of development that also affects other areas of development.

Visual impairment may affect motor development. If a child cannot see well enough to move about alone and to practice crawling, walking, or running safely, the child may become delayed in motor development.

Children Have Individual Rates of Development

Children have individual rates of development. Some children seem to be ahead of others in their overall development. Other children may be behind but will catch up later or will catch up in one area of development but not in another.

One child may be using many words while the second child is not; but the second child can ride a tricycle while the first child cannot.

Adapted from:

Osborne, S., Kniest, B.,
Garland, C., Moore, D., &
Usry, D. (1993).
*Specialcare curriculum
and trainer's manual.*
Lightfoot, VA: Child
Development Resources.



Play Is Essential

Individual Development Depends Both on Inborn Characteristics and Environment

The path of individual development depends both on inborn characteristics and on a child's environment. Children seem to be born with a range of possible abilities in different areas, such as intelligence. An environment that gives a child lots of different experiences will help a child to strengthen his natural abilities.

A child born with a serious hearing impairment will have problems developing spoken language. Pronunciation, vocabulary, and speaking in sentences will all be affected. An environment rich in communication experiences, started early in the child's life, will help the child develop communication skills.

Development Is a Combination of Maturation and Learning

Development is a combination of maturation and learning. Children cannot learn certain things until they are physically ready.

We cannot teach a child to ride a tricycle just by telling her how. The child's legs must be long enough to reach the pedals and strong enough to push them. The child must have the strength to grip the handlebar. The child must have a sense of balance. The child must be able to alternate her legs and feet to cycle.

Adapted from:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *Specialcare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.



Getting Involved in Play

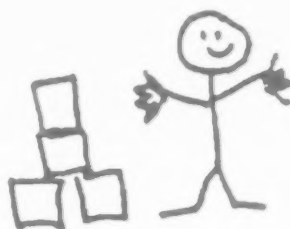
The Importance of Play

Play is essential to children's development. It is the way in which children grow and learn. Through play, children learn to solve problems, get along with other people, and use their bodies to explore the world around them.

A child can develop creativity and imagination when playing alone with a toy. When children play with others, they grow emotionally and learn social skills. Toys and games should be selected to allow children to use them in many ways, based on their development and interests.

Social Interaction

In group respite settings, it is important for caregivers to help children with disabilities and children without disabilities to interact socially.



Sometimes children with disabilities have difficulty learning social behaviors. At first, they may need a caregiver's assistance to interact with others.

Children with disabilities may have more subtle or unusual ways to communicate or signal for attention. They may have a slower response time, be delayed in language, or have physical limitations that affect their interactions.

Getting Involved in Play

Once a caregiver is aware of how a child's disability affects his or her ability to interact with other children, you can help by modeling appropriate techniques to engage the child and by teaching those techniques to other children. In order to promote social interactions, caregivers should:

- Encourage children to play together and acknowledge them when they do
- Remember that too much attention from adults may interfere with the children's interactions
- Teach children specific ways to ask other children to play, share toys, take turns, express affection, and help other children

Sometimes staff of community programs think that they will have to make extensive changes to their programs to include children with disabilities. Often times only a few accommodations are needed to meet the needs of children with disabilities. Valuable respite to families with children with disabilities can be offered by providing the same kinds of appropriate experiences that characterize quality programs for all children.

Adapted from:

Hanline and Blair (1988). Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *Specialcare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.

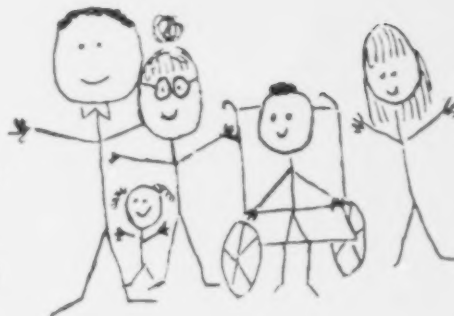


Getting Involved in Play

Guidelines for Caregivers' Involvement in Play

Caregivers should play with a child by following the child's lead. This may take some practice. Here are some guidelines to help you.

- Observe** Watch children to see what skills they already have and what they like to do.
- Follow** Join in when a child invites you. Let the child be in control and play at his level.
- Be creative** Discover or rediscover the many different ways to play.
- Be safe** Be sure toys, activities, and play space are safe and developmentally appropriate for the child. See page 10-15 for the health and safety checklist we give families. Consider these things as you work with families and children.
- Have fun** Relax and enjoy each other's company.



7

Section 7

children with
special needs

Understand Each Child's Needs

Children with Special Needs

There is a wide range of disabilities and special health needs. We will use this section to give you some information on some of the more frequently occurring disabilities. As you read, remember that the same disabilities and health conditions can look very different in individual children. Families are the experts on their own children! They will give you specific information about their children's special gifts and special needs.

Attention Deficit Disorder (ADD) / Attention Deficit Hyperactivity Disorder (ADHD)

Children with these diagnoses have very short attention spans. They often have difficulty focusing on tasks. They may be impulsive, and, if they are diagnosed with ADHD, they are physically active as well. Children with ADD or ADHD often need very structured routines in order to feel comfortable. They may take medication to improve their attention spans. Families may also have clear rules for these children and specific consequences for following or not following the rules.

Questions to Ask:

- Does Wendell have a routine during the day? How does that work?
- Does Wendell take medication? When does he take it? Does he have a special medication routine? Does the medication have any side effects I should know about?

Understand Each Child's Needs

- Do you have household rules that Wendell must follow? What are the consequences if he doesn't follow the rules? What about rewards if he does follow them?

Autism

Children with autism often have trouble with social and communication skills. Some children with autism never speak at all; others achieve academic success but may have less than fully mature social skills. Children with autism may need to have the same routine every day to feel comfortable.

Questions to Ask:

- How does Joey communicate? How do you make sure that his needs are met?
- Does Joey have a set schedule? What is his routine?
- What is the best way to help Joey make transitions?

Blindness/Visual Impairment

Visual impairment is less severe than blindness. Most people who have a visual impairment have some level of vision. They may see light, or they may see fuzzy images. They may have vision like they are looking through a tunnel. They may have spots in their vision. Children who have a visual impairment may have trouble seeing, even when wearing contact lenses or



Understand Each Child's Needs

eyeglasses. Because children often learn to use their bodies by reaching for things that they see, children with visual impairments may show delays in gross motor and fine motor skills.

Questions to Ask:

- What type of visual impairment does DiShannon have? What can she see?
- How is DiShannon doing with her motor skills?
- How does DiShannon move around? What is the best way to lead her when we are walking together?
- Is DiShannon familiar with the rooms in the house? (If you are working with DiShannon in your home, it may take some time for her to learn the layout of your rooms. She will need to explore to find out where the furniture is or where the rug stops. Be particularly aware of safety issues. Are there glass objects she could knock over? Are there steps that she could fall down? Stay close with DiShannon as she learns about your home.)
- When I set the table for dinner (or set up another activity), where should I put DiShannon's things so she can find them?

Deafness/Hearing Impairment

Deafness is the inability to hear. Deaf children may need to watch lips or to learn a language of gestures, like sign language. Hearing impairments are less severe than total



Understand Each Child's Needs

deafness. Children with hearing impairments may hear only loud noises. Sometimes, they may only hear people when they speak at very high or very low pitches. They may be fitted, as early as infancy, with hearing aids.

Questions to Ask:

- What type of hearing impairment does Juan have? What can he hear?
- How does Juan communicate?
- How do you communicate with Juan?
- How do you get Juan's attention?
- Does Juan use a hearing aid? How does it work?

Emotional Disturbance

Children with emotional disturbances usually have trouble with social skills or making friends. There are many different kinds of emotional disturbances. Some children are very sad or react in ways that you would not expect. For example, they might laugh when they are hurt. Some children with emotional disturbances are very anxious and difficult to calm. Others may be very aggressive. They may fight a lot, or they may be very defiant. As a caregiver, you might need to watch children closely on the playground and with other children. Children with emotional disturbances frequently need a lot of encouragement and praise.



Understand Each Child's Needs

Questions to Ask:

- What type of emotional disturbance does George have? What does he do that is unusual?
- How do I calm George when he is upset?
- Does George take medication? Does he have a medication routine?
- How do you try to control George's behaviors? If he fights with a child, or doesn't listen to me, what should I do?
- What does George enjoy doing? What kinds of things is he good at?

Learning Disability

A learning disability affects the way that a child understands or gives information. A child with a learning disability may have trouble with reading, writing, math skills, listening, speaking, or using logic. Dyslexia is an example of a learning disability. The person with dyslexia has trouble reading and writing, though he may be smart and does not have any hearing or visual impairments. Some children with learning disabilities might have trouble understanding what you are saying to them. Some might have trouble remembering what you told them just a few minutes before. Caregivers working with children with learning disabilities might see motor delays or language delays as well.



Understand Each Child's Needs

Questions to Ask:

- How does Lahn learn best?
- What is the best way to present information to her? Is it better if I tell her something, draw a picture, or write it down?
- What activities frustrate Lahn?

Mental Retardation

Children with mental retardation may have difficulty learning and remembering what they have learned. They often learn new skills at a slower rate. Because mental retardation is usually diagnosed through testing, a family may be able to tell you at what age level their child is operating. For example, a child may be 8 years old, but a family may tell you that he functions at a 4 year old's level. This is valuable information! Think about the development of a child not his size or age. He may be big but may still have trouble playing games with lots of rules.

Questions to Ask:

- What does Mark do well? What should I encourage him to do on his own?
- In what areas does Mark need help? How can I help him?



Understand Each Child's Needs

Orthopedic Impairment

An orthopedic impairment affects the bones, muscles, and/or the way the body moves. Many diagnoses are included in this category. A child who has a leg amputated is considered to have an orthopedic impairment. Children with muscular dystrophy, which causes muscles to deteriorate over time, develop orthopedic impairments. Children with spina bifida, which limits the brain from sending messages to healthy muscles because the spinal cord was not closed at birth, or cerebral palsy, which also limits the brain's ability to control muscles, are considered to have orthopedic impairments. Children with orthopedic impairments generally show motor delays. Depending on which of their muscles are affected, children may also have trouble communicating, eating, or toileting.

Questions to Ask:

- What type of orthopedic impairment does Tawann have? What muscles are affected? What activities (eating, moving, picking up small objects, communicating, etc.) are affected? How can I support Tawann in those activities?
- What is the best way to hold Tawann so he is supported and comfortable?
- What is the best way to move him from place to place?
- What is the best way to position Tawann?
- Can I help with any physical therapy routines?



Understand Each Child's Needs

Severe and Profound Disabilities

Children with severe and profound disabilities usually need extensive help with self-care. They may have more than one disability, such as having mental retardation together with seizures, cerebral palsy, or troubling behaviors.

Questions to Ask:

- What kinds of activities does Arthur enjoy? How do I make my time with him fun?
- How do I help Arthur with feeding? Toileting? Washing?

Speech Impairment/Language Disorder

Children with speech impairments have difficulties producing some sounds or have trouble with the way that their voices sound. Some people with speech impairments get stuck on sounds and say them over and over. Some people may replace sounds with other sounds. For example, they might say thay instead of say. Some speak too loudly or keep their voices at a very high pitch. A language disorder may be diagnosed when a person has trouble using words to communicate clearly or understanding what is said to him, although he can hear.

Questions to Ask:

- How does Julia communicate?
- What is the best way to communicate with Julia?



Understand Each Child's Needs

- Does Julia see a speech therapist? Can I help with any speech therapy routines?

Traumatic Brain Injury (TBI)

TBI occurs when a person gets a sharp blow to the head or an object goes into the brain. Symptoms of people with TBI will vary according to what parts of the brain were injured. Children with TBI show a variety of cognitive, physical, social, emotional, and adaptive delays. When you work with children with TBI, it will be important for you to learn from individual families how their children have been affected and how you can help.

Questions to Ask:

- How is Darius affected by his TBI?
- How can I help?

Special Health Care Needs and Chronic Illness

Like children with other special needs, children with special health care needs are a diverse group. Even children with the same diagnosis can be very different. Working with children with special health care needs can be a very different experience from working with children with other disabilities. Some children might require special diets or feeding procedures. Other children may need machines to maintain or to monitor their heartbeat and their breathing.

Understand Each Child's Needs

Allergies

Some children need to avoid certain substances because they are allergic to them. The substances that children are allergic to are called allergens. Children might be allergic to specific foods, insect bites or stings, or animals. They might be allergic to certain types of material. For example, some children are allergic to the latex in some plastic gloves and in rubber balloons. Some children are allergic to pollen in the air or smoke. Children who have allergies react differently when they come in contact with their allergens.

Questions to Ask:

- What is Josie allergic to?
- What do I need to do to prevent exposing her to that allergen?
- How does Josie react when she is exposed to the allergen?
- How can I help her if she is exposed?

Asthma

Children who have asthma have difficulty breathing at times. An asthma attack may include gasping for air, shallow breathing, wheezing, dry coughing, and/or vomiting. Allergens generally trigger attacks. They are more frequent in cold weather and may occur after exercise.



Understand Each Child's Needs

Questions to Ask:

- What causes Jouaquin's asthma attacks? Can I prevent him from being exposed to that? How?
- What do Jouaquin's asthma attacks look like?
- How do I help Jouaquin when he is having an asthma attack? Does he take medicine? How does he take it?
- How long do Jouaquin's attacks usually last? Should I get concerned if they last beyond a certain time? What should I do if they last that long?

Cancer

Cancer is a group of abnormal cells that multiply uncontrollably. Sometimes, these cells can travel through the body and affect different body organs. Cancer affects children differently depending on the parts of the body where the cancer has grown. Speak with families about their children's symptoms and how you can help them have a good time in respite. Be aware that children with cancer may experience a lot of pain. They may be weak and tire easily. Plan plenty of rest periods in your play. Children with cancer may feel nauseous at mealtimes. Talk with families about special diets for their children and special medication routines.

Questions to Ask:

- How can I make Micah comfortable during respite?
- When you are playing with Micah, does he tell you that he is tired? If not, how will I know when Micah needs to rest?



Understand Each Child's Needs

- Does Micah take medications? What is his medication routine? What side effects should I be aware of?
- Does Micah eat a special diet? What foods should he not have? Do some foods sit better in his stomach than others? What are they?
- What activities does Micah enjoy the most?

Congenital Heart Disease

Children with congenital heart disease have trouble with their hearts from birth. Their hearts may not beat regularly, they may stop beating at times, or they are not structured the way they need to be to do their jobs. Children with congenital heart disease may have had surgery or may need surgery in the future. Sometimes, they use heart monitors to track their heartbeats. As a caregiver for these children, you might need to learn how to use these machines and what to do if the alarm goes off.

Questions to Ask:

- How does Sridhar's heart disease affect him? What activities does he enjoy? What should we avoid doing?
- Does Sridhar use a heart monitor? How does it work? How do I know if there is a problem?
- How should I respond if there is a problem?



Understand Each Child's Needs

Cystic Fibrosis

Cystic fibrosis is a condition that causes the lungs and other organs in the body to produce a lot of mucus. This mucus can build up in the child's system and affect the way that the organs function. Children with cystic fibrosis may cough a lot as they try to clear their lungs of mucus. They generally need special diets and medications to help them process their foods. They may also need their caregivers to give them physical therapy at mealtimes to help them clear their lungs.

Questions to Ask:

- What is Joanna's medication routine? What is the most comfortable way for me to give her medicine?
- Does Joanna ever refuse her medicine? What do I do if she refuses the medicine from me?
- Do I need to give Joanna chest PT (physical therapy)? How do I do that? When do I do that?

Diabetes

Children with diabetes do not process sugar the way that other people do. Children with diabetes follow special diets and may have exercise built into their routines. They may need to have their blood sugar tested during care and often use insulin injections to regulate blood sugar levels. Caregivers will need to monitor children for signs of high or low blood sugar.

Understand Each Child's Needs

Questions to Ask:

- How does Matt's diet work? Does Matt ever refuse the food that he needs to eat? What should I do if he refuses food?
- How do you monitor Matt's blood sugar levels? Does he take blood tests? How do I help him do that? When should he test his blood?
- Does Matt take insulin? How do I help him take his medication? When does he take it?
- What does it look like when Matt has low blood sugar? What do I need to do if he does? What does it look like when he has high blood sugar? What do I need to do if he does?

HIV/AIDS

HIV, the virus that causes AIDS, attacks the immune system. Children with AIDS are vulnerable to infections. They may have other health conditions for which they will need special care. For example, children with AIDS may have respiratory or other infections, chronic diarrhea, and growth and other developmental delays. Many people are afraid to work with children with HIV/AIDS although it is transmitted only by an exchange of bodily fluids. It is important for caregivers to protect and educate themselves by learning the facts about this disease and how it is transmitted. Section 9 includes Universal Precautions Guidelines that will help protect you from infections and disease.



Understand Each Child's Needs

Questions to Ask:

- Do I need to take any special precautions when caring for Martha?
- How is HIV/AIDS affecting Martha?
- How can I best support her in her development?
- Does Martha take medication? What is her medication routine? Are there side effects that I need to know?
- Does Martha eat a special diet? What foods should I avoid feeding her?

Kidney Disease

The kidneys clean waste out of blood. Children who have kidney disease have trouble with the way that their kidneys function. They might have trouble with urination. Children with kidney disease may need to watch their diets and drink plenty of water. Children with kidney disease may go to a hospital on a regular basis for dialysis, a treatment through which waste is cleaned from the blood by a machine.

Questions to Ask:

- How does kidney disease affect Michael? What activities does he enjoy? What activities should I avoid doing with him?
- Does Michael take medication? What is his medication routine?

Understand Each Child's Needs

- What foods should Michael avoid eating? What else should I know about his diet?
- How often should Michael drink fluid? What fluids do you want me to give him?

Seizure Disorders

A person who has a seizure temporarily loses control over parts of his or her body. Seizures happen when there is a sudden change in the way that the brain is functioning. There are several types of seizures. Some children who have seizures have a change of consciousness for a short period. Others show brief, marked changes in movement or activity. Children with **epilepsy** have repeated seizures. Children with seizure disorders often take medication to control their seizures and may eat special diets. In general, people can help a person who is having a seizure by helping him lie down, preferably on his side. Clear the area of anything that he might get hurt on during the seizure.

DO NOT TRY TO HOLD ONTO THE PERSON OR TRY TO CONTAIN HIM DURING THE SEIZURE!

Questions to Ask:

- How do I know when Jerry is having a seizure?
- Is there anything that you know of that triggers seizures for Jerry? Are there any activities that we should avoid?
- How do I help Jerry when he is having a seizure?



How Special Needs Affect Development

- How long do Jerry's seizures typically last? When should I call for more help?
- How does Jerry feel when the seizure is over? How can I help him recover?
- Does Jerry take medication? What is his medication routine?
- Does Jerry eat a special diet? What foods should he avoid?

How Special Needs Affect Development

An awareness of how special needs affect development is a good starting place for caring for a child with a special need. Different conditions affect development in different ways. When working with children with special needs, you can use this information to plan activities for them. Remember that some children with special needs, especially children with health concerns, have spent some of their childhoods sick, in hospitals, or otherwise confined. These children may not have had many of the experiences that encourage development. Work with families to plan activities that encourage development in their children.

- **Children with speech or language impairments might**
 - have greater receptive (understanding) than expressive (speaking) language skills
 - substitute one sound for another such as wabbit for rabbit
 - omit sounds, such as saying han for hand



How Special Needs Affect Development

- distort sounds such as saying thay for say
- not use many words
- speak in short sentences
- have trouble understanding what others are saying
- **Children with mental retardation might**
 - have a hard time following directions
 - not pay attention for a very long time
 - need extra help with transitions
 - have a hard time remembering things
 - need help applying what they learned
- **Children with learning disabilities might**
 - have difficulty in processing information
 - have difficulty in recalling information
 - have difficulty with coordination
 - Children with motor disabilities might
 - walk or move in an unusual way
 - be very clumsy
 - fall or stumble very easily, especially on uneven ground
 - have trouble controlling certain body parts
 - need special equipment like crutches, braces, or a wheelchair
 - not be able to grasp toys securely
- **Children with hearing impairments might**
 - not talk very much
 - leave out certain sounds when they speak
 - talk in a flat sounding voice without expression
 - misunderstand what you say
 - have a short attention span and be easily distracted



How Special Needs Affect Development

- not turn toward the sound of voices
- watch your mouth very closely when you talk
- **Children with visual impairments might**
 - blink, squint, or rub their eyes quite often
 - hold books or other objects very close to their faces
 - cover one of their eyes or tilt their heads in an unusual way
 - complain of headaches, dizziness, itchy eyes, or fuzzy vision
 - trip over small objects
- **Children who have behavioral, social, or emotional disabilities might**
 - be aggressive
 - withdraw from other children and not talk or play with the group
 - have extreme outbursts of crying, tantrums, or yelling
 - have unusual behaviors that they often display, such as waving their hands in front of their eyes or making noises
 - be impulsive
 - have a short attention span

Adapted from:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *SpecialCare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.



High Risk Signs

High-Risk Signs

The following list includes a sample of behaviors that may indicate that a child is having problems. You might be the first to notice an unusual behavior. By telling families about the things you notice in a supportive way, you give them valuable information about their children. Remember that any child may demonstrate some of these behaviors and not be having difficulty. However, becoming familiar with these high-risk signs will help you be more aware of the special needs of children.

- **Vision**
 - Squints, tilts, or turns head to look at angles
 - Closes one eye
 - Often bumps into things or falls on the playground
 - Frequently rubs eyes or complains that eyes hurt
 - Has red, watering, or encrusted eyelids
 - Sometimes or always crosses one or both eyes
 - Frequently holds books or other objects very close to eyes
- **Hearing**
 - Does not turn toward you when you call his or her name softly
 - Shows marked reaction to sudden noises
 - Attends to music or stories for less time than other children
 - Has unusually unclear speech compared to other children



High Risk Signs

- Uses gestures rather than words to communicate after age 2
- Has frequent earaches or fluid running from ears
- Talks in a very loud or very soft voice
- Always turns the same ear toward a sound
- Does not respond when you call from another room

- **Motor**
 - One side of the body is more coordinated than the other
 - Hands are shaky or clumsy when doing fine motor tasks
 - Cannot balance on one foot for a short time by age 4
 - Cannot cut with scissors by age 4
 - Cannot throw a ball overhand or catch a large ball by age 5

- **Social-Emotional**
 - Interactions with adults:**
 - Has an unusual number of attention-getting behaviors

 - Interactions with other children:**
 - Avoids certain children
 - Latches onto one particular child
 - Disrupts other children's play often
 - Does not play in group games or pretend play by age 4
 - Does not share or take turns by age 5



High Risk Signs

Individual behaviors:

- Displays self-abusive behaviors (hurts herself)
- Displays self-stimulatory behaviors (rocking, spinning, picking)
- Overreacts to unexpected stimuli (loud noises, sirens)
- Reacts unusually strongly to the feel of certain substances or textures
- Seems uncomfortable being touched by others
- Has toileting problems at least once a week by age 4

• Language

- Does not show interest in books or listening to stories
- Does not follow simple verbal directions
- Is not talking at all by age 2
- Echoes questions or other phrases after age 3
- Is not talking in short sentences by age 4
- Is not understood by people outside the family by age 4

• Cognitive

- Cannot answer simple questions about a story by age 3
- Does not give reasonable answers to such questions as *What do you do when you are sleepy?* or *What do you do when you are hungry?* by age 4
- Does not demonstrate simple problem-solving skills such as completing puzzles or following patterns for bead stringing by age 4



Finding Additional Information

- Does not seem to understand the meaning of the words *today*, *tomorrow*, and *yesterday* by age 5
- Does not demonstrate memory skills such as repeating short lists of numbers or telling what's missing from a group of objects by age 5

Adapted from:

Osborne, S., Kniest, B., Garland, C., Moore, D., & Usry, D. (1993). *SpecialCare curriculum and trainer's manual*. Lightfoot, VA: Child Development Resources.

Where to Find More Information on Special Needs

There is an incredible range of disabilities and special health needs. Families and caregivers can use the following agencies in their communities to gather resources on specific special needs.

- Local early intervention programs
- Public school, preschool, or special education programs
- Doctors, nurses, therapists, social workers, and teachers
- Local, college, and university libraries
- Parent Resource Centers
- Parent to Parent Networks
- Local hospitals

Finding Additional Information

- Parent Training Information Centers
- National Information Center for Children and Youth with Disabilities (NICHCY), call toll-free 1 (800) 695-0285
- *Exceptional Parent: Parenting Your Child or Young Adult with a Disability* (magazine)
- National Health Information Center, call toll-free 1 (800) 336-4797
- Internet (accessible through many "on-line" services)



Notes on this Section



8

Section 8

becoming a
caregiver

Getting Ready for Training

Congratulations!

You have learned some basic information for providing respite care to children with special needs. The next step is to participate in personalized training with a family. In this section, we have included sample interview questions families may use to help them choose a caregiver. Maybe you have already made a match with a family and are ready to begin specific training!

As you talk and train with families, be active and open. Ask questions! Find out if this will be a good match for you. If you are not comfortable about working with a child or family, address that early. Families want caregivers to let them know if they cannot work with their children.

What Can I Contribute As a Respite Caregiver?

Your life experiences, education, training, and openness to learning can be valuable to families looking for a respite caregiver. Think about your strengths and use this worksheet to write down what you have to offer. You might want to tell families about these strengths when interviewing with them.



Getting Ready for Training

- I want to provide respite care because . . . _____

- I have these skills to offer . . . _____

- I have these life experiences that will help me care for children
with disabilities and build successful relationships with their families . . .



Sample Interview Questions

Sample Interview Questions

You may be asked several of these questions when you interview with families:

- Tell us about your education and/or experience in working with children.
- Discuss your experience working with children with special needs.
- Why are you interested in providing respite care services?
- Describe your strengths. How would you describe yourself?
- Why are you the right person for the job?
- What are your thoughts about families who have children with special needs?
- What would you do if we disagreed about something?
- If my child had to be taken to the hospital for an emergency, what steps would you take?
- How do you believe children's difficult behaviors should be managed?
- What would you do if a child deliberately hit another child?
- What would you do if you found a child with an open bottle you suspect is poison?



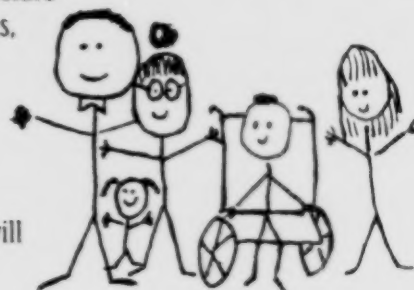
Training Designed for You

- Are you willing to take my child out on activities?
- Describe a difficult problem you've had to handle with a child. How did you handle it?
- Tell me about any special training or experience you might have.
- How would you know if my child likes a particular food or activity if he or she is not yet verbal?
- Are you willing to have a criminal background check?
- Do you have CPR, First Aid, and medication assistance training?
- Do you have a valid driver's license?

Personalized Training

In the Partners workshop, families learn about and are prepared for personalized training. Families are given a structure to help them train caregivers. In the next few pages, we have included information on that structure.

Think about ways that you can help plan your personalized training. Different people learn differently and will have different questions for families. The information on the following pages will help you share your preferences, thoughts, and feelings about training with families. Through sharing information, the training will be a positive learning experience for everyone.



Developing a Personalized Training Plan

Developing a Personalized Training Plan

The Partners Plus model is based on the belief that families know best how to care for their own children and that they have the skill and knowledge needed to train their own respite caregivers. The family and caregiver together decide the specific amount of individual training needed to provide for a child. Training time will vary according to child, family, and caregiver needs.

There are four simple steps to help a family develop a personalized training plan.

Step 1: Identify training goals.

What will a family want a caregiver to learn about their child and family routines?

Step 2: List training methods.

What methods will a family use to teach their caregiver?

Step 3: Use resources to help train your caregiver.

What information will a family use to help their caregiver learn?

Step 4: Evaluation

How will a family and caregiver know when the caregiver has learned a specific skill or routine?

Sample Personalized Training Plan

Sample Personalized Training Plan

Child's Name: Maria

Date: May 10, 1997

Routine: Lunchtime

Time of Day: Noon - 1:15 p.m.

Step 1: Training Goal

My respite caregiver will be able to feed Maria lunch.

Step 2: Training Methods

My caregiver will watch lunchtime feeding.

My caregiver will assist in feeding Maria.

My caregiver will feed Maria with some assistance.

I will watch my caregiver feed Maria.

Step 3: Resources

I can give my caregiver:

- a handout on feeding techniques developed by Maria's occupational therapist.
- a handout on special feeding problems in children with cerebral palsy.
- a video of lunchtime routine taped by us at home.

Step 4: Evaluation

I will ask my caregiver questions about skills and comfort in feeding Maria.

I will watch my caregiver feed Maria two bites.

I will watch my caregiver prepare and feed lunch to Maria.



How I Learn Best

How I Learn Best

One way to help families plan your training is to think about how you learn best. Families can choose a variety of ways to train. These can include written materials and instructions; print materials; audiotapes or videotapes; oral instructions; or demonstration, practice, and feedback.

How do you learn best? Use this worksheet to check the ways that you learn best. Share this with families when you are developing a training plan.

- ☐ Written materials
- ☐ Audiotapes
- ☐ Videotapes
- ☐ Oral instruction
- ☐ Demonstration, opinions, and practice
- ☐ Other

Partnering with Your Family

Families learn in the Partners workshop that caregivers learn in many different ways. It is helpful to talk with families about how you learn. Before you begin training, talk with families about how you think you will learn their child's routine best. Work with them to develop a training plan that incorporates their teaching style and your learning style.



Tips for Learning

You may not be sure about how you learn best and may want families to proceed with their training plan. During this process, you may discover that you learn best with certain training techniques or that other techniques are not as effective for you. Families learn that it is important to be flexible and adapt their training plan to best meet everyone's needs.

The following are some techniques families have been taught in group training to help a caregiver learn their child's routine:

- Provide written information.
- Ask caregivers to repeat what they thought they heard.
- Ask caregivers to assist in a routine or activity.
- Encourage caregivers to ask questions.
- Ask caregivers to demonstrate the activity or skill.
- Ask caregivers questions.
- Share personal experiences.
- Encourage caregivers to share their ideas.

Tips for Learning

- **Discuss training ideas with families.**

If you have identified areas of training that you think will help you in providing care, then share your ideas.



Tips for Learning

- **Give feedback.**

If a teaching method did not help you learn, be sure to tell the family so they can try another way.

- **Write down questions or important facts.**

Bring a notepad with you when you work with a family and their children. You may note something and want to refer back to it or share it later with the family.

- **Ask questions.**

If you do not understand something, then ask for more information.

- **Share new information that you discover with families.**

Families will appreciate knowing you are learning more on your own.

Training Ideas

A major part of successful training is the ability to identify what you want to include in a training plan. Once you match with a family, you may still have concerns about being adequately trained. Use this worksheet to identify others areas of training you might need. These areas may be related to your need for additional knowledge, skills, or comfort in caring for the child or working with the family. Share this information when you meet with a family to help them know other areas to include in your training.



Essential Information for Caregivers

Knowledge	What more do you need to know about working with this child?
Skills	What do you need to learn to do to work with this child?
Comfort	What do you need to increase your comfort level in working with this child?

Essential Information for Caregivers

There is essential information that a caregiver will want to feel comfortable in providing respite care. Be sure to talk with a family about these issues before completion of your individual training. Use this as a checklist to make sure you have the necessary information before providing respite care.

- _____ **Emergency phone numbers**
- _____ **Emergency plan**
- _____ **Medication schedule**
- _____ **Home safety issues**
- _____ **How to use equipment**
- _____ **Household routines**
- _____ **Household rules**
- _____ **Information about siblings**



Notes on this Section



9

Section 9

resources

Defining Universal Precautions

Resources

The following pages contain valuable information and may be used as a resource for families and caregivers.

Universal Precautions Guidelines

In order to prevent disease, it is important to practice good personal hygiene and to take some precautions, especially when working with children. This is sometimes referred to as universal precautions.

The Occupational Safety and Health Administration (OSHA) has established methods people can use to avoid the transmission of infections and disease. By practicing the following methods, you can help yourself, your family, and the child you provide respite for stay well.

Infectious diseases can be prevented with planning and preparation. Always practice good personal hygiene and wash your hands often. Washing your hands is the most important defense to avoid contracting or transmitting an infectious disease. Good health and up-to-date immunizations are important. Always be careful and act as if all people you come into contact with are potentially infected. There is no way to determine if a person is infected just by looking at them.



Defining Universal Precautions

In general, it is good to follow these basic precautions when you provide care:

- Wear disposable gloves when it is possible that you will contact blood or body fluids. This contact could occur directly from the person or indirectly through contact with soiled clothing, diapers, or other articles.
- Remove gloves by turning them inside out beginning at the wrist and pulling them off.
- Throw away damaged gloves.
- Do not clean or reuse disposable gloves.
- Avoid touching any items while you are wearing soiled gloves.
- Change gloves when you touch different people.
- Wear protective coverings, such as a mask, eyewear, and/or a gown, whenever you may contact body fluids that might splash.
- Cover any cuts, scrapes, or skin irritations you may have with clothing or bandages.
- Use breathing devices, such as disposable resuscitation masks and airway devices.
- Avoid needle sticks.
- Perform all procedures in such a way as to avoid splashing, spraying, splattering of body fluids.



Defining Universal Precautions

- Avoid touching your face after exposure to body fluids before you wash your hands.
- Remove soiled clothing as soon as possible.
- Clean and disinfect all areas soiled by blood or other body fluids.
- Use approximately 1/4 cup bleach to 1 gallon of water to clean and disinfect soiled surfaces and other items.
- Clean up spills immediately.
- If spills are mixed with sharp items such as broken glass, use tongs or two pieces of cardboard to pick them up, not your hands.
- Use an absorbent material to clean up a spill. Discard the used absorbent material.

If you think that you have been exposed to an infectious disease, wash the area of contact immediately. Exposure usually involves contact with potentially infected blood or fluids through a needle stick or the mucous membranes (eyes, nose, mouth) or inhaling potentially infected airborne droplets.

Infectious diseases can typically be transmitted in four ways: 1) by direct contact with an infected person, through body fluids or through contaminated needles; 2) by contact with a soiled object; 3) by inhaling air exhaled by an infected person; 4) from a bite from an animal, an insect, or an infected person.

Preventing the Spread of Disease

If you are working with a child who has an infectious disease, ask the family how it is transmitted and what you should do to protect yourself. Some infectious diseases that you should be aware of are herpes, meningitis, tuberculosis, hepatitis, and HIV/AIDS. Please refer to the following chart for more information.

How Diseases Are Transmitted

Disease	Signs and Symptoms	Mode of Transmission	Infective Material
Herpes	Lesions, general ill feeling, sore throat	Direct contact	Broken skin, mucous membranes
Meningitis	Respiratory illness, sore throat, nausea, vomiting	Airborne, direct and indirect contact	Food, water, mucus
Tuberculosis	Weight loss, night sweats, occasional fever, general ill feeling	Airborne, direct and indirect contact	Mucus, broken skin
Hepatitis	Flu-like, jaundice	Direct and indirect contact	Blood, saliva, semen, feces, food, water, other products
HIV/AIDS	Fever, night sweats, weight loss, chronic diarrhea, severe fatigue, shortness of breath, swollen lymph nodes, lesions	Direct and indirect contact	Blood, semen, vaginal fluid

Adapted from:

American National Red Cross. (1993). *Preventing disease transmission* [Booklet]. St. Louis, MO: Mosby Lifeline, Mosby-Year Book, Inc.



Preventing the Spread of Disease

Hand Washing

The most important defense against spreading infectious diseases is thorough hand washing with soap and water. Gloves may not always be necessary or even possible to use when reacting to an emergency, but it is extremely important to wash your hands immediately afterward!

There are particular times that you should always wash your hands. It should be done frequently:

- Before putting on a smock in preparation for working with children
- Before drinking, eating, or smoking
- Before handling clean utensils or equipment
- Before and after handling children's food
- Before and after going to the bathroom
- After contact with body secretions, such as blood, urine, feces, mucus, saliva, or drainage from wounds
- After handling soiled diapers, pads, garments, or equipment
- After caring for any child, especially those with nose, mouth, or ear discharge
- After removing disposable gloves
- After removing smock or shirt when leaving the work area

Adapted from:

California State Department of Education.
(1983). *Techniques for preventing the spread of infectious diseases*
[Booklet]. Sacramento, CA: Author.



Protocol for Hand Washing

Protocol for Hand Washing

Essential Steps

1. Remove all jewelry.
2. Wet hands with warm, running water.
3. Apply liquid soap and lather well.
4. Wash hands, using a circular motion and friction, for 15 to 30 seconds.
5. Rinse hands well under warm, running water.
6. Repeat steps 3 through 5.

Key Points and Precautions

Jewelry should not be worn when working with students who require repeated physical contact and care. Microorganisms can become lodged in settings or stones of rings.

Warm water, combined with soap, makes better suds than does cold water. Hot water removes protective oils and will dry skin. Running water is necessary to carry away dirt and debris.

Liquid soap is preferred to bar soap. Bacteria grow on bar soap and in soap dishes.

Include front and back surfaces of hands, between fingers and knuckles, around nails, and the entire wrist area. Avoid harsh scrubbing to prevent skin breaks.

Hold hands under the water so that water drains from wrist area to fingertip.

All remaining bacteria and soil should now be removed.



Protocol for Hand Washing

7. Wipe surfaces surrounding sink with

a clean paper towel and discard.

8. Dry hands well with paper towels
and discard towels immediately.

9. Apply lotion as desired.

Damp surfaces promote the
growth
of bacteria.

Because of frequent hand
washing, it is important to dry
gently and thoroughly to avoid
chapping. Chapped skin breaks
open, thus permitting bacteria to
enter one's system.

Lotion helps keep skin soft and
reduces chapping.

Source:

California State Department of Education. (1983). *Techniques for preventing the spread of infectious diseases*. Sacramento, CA: Author.



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References on Adult Learning

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Rossmann, M.H., Fisk, E.C., and Roehl, J.E. (1984). *Teaching and Learning Basic Skills: A Guide for Adult Basic Education and Developmental Education Programs* (New York: Teachers College Pr.).

Training Resources

Creative Training Techniques Newsletter
Lakewood Publications
50 S. 9th St.
Minneapolis, MN 55402

(800) 707-7749

<http://www.trainingsupersite.com/publications>



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Phone: 1-800-473-1727 or (919) 490-5577; FAX: (919) 490-4905
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General Information About Respite Care

Background

Respite Care programs emerged in the late 1960's as a result of the deinstitutionalization movement with the belief that the best place to care for a child with disabilities was in the child's home and community. Respite care became an essential component in the overall support services that families need to provide home care. Recognizing the effectiveness of respite care services, in 1986, Congress passed the *Temporary Child Care for Children with Disabilities and Crisis Nurseries Act* (as amended). This Act established federal funding for respite care demonstration projects. Administered through the U.S. Department of Health and Human Services, Children's Bureau, competitive grants have been awarded to States since 1988 to assist private and public agencies in developing model respite care services across the United States.

Purpose

Respite care programs provide temporary relief for families or caregivers. Additional family benefits include: allowing the family to engage in daily activities thus decreasing their feelings of isolation; providing the family with rest and relaxation; improving the family's ability to cope with daily responsibilities; maintaining the family's stability during crisis situations; helping preserve the family unit by lessening the pressures that might lead to divorce, institutionalization, neglect and/or child abuse; and, making it possible for individuals with disabilities to establish individual identities and enrich their own growth and development.

What is Respite Care?

The federal legislation defines respite care as in-home or out-of-home temporary, non-medical child care for families who have children with disabilities, chronic, or terminal illnesses. Most respite care programs offer services to families on a sliding fee scale with hourly and/or daily rates. Respite care services can range from a few hours of care up to three months of care depending on the needs of the families and the type of respite care program model available in a community. The ages served by respite programs

range from infancy to adulthood. Often programs serve a particular disability or illness (e.g., children who have HIV-related conditions, children who are medically fragile, children with mental retardation).

Many respite care services are incorporated within larger social service agencies both at the community and/or state levels which provide an array of support services to families. Some of these support services can include: family counseling; family support groups; parent training; service coordination; assistive equipment services; and, access to medical services.

Respite Care Program Models

Respite care program models for each local service area may differ according to the needs of families/caregivers within the community. For example, some respite care programs may utilize an available bed in a health care facility or state institution for families who require extended respite options and whose child requires skilled care; whereas, other respite care programs may only offer time-limited (a few hours) services in the family's home. In addition, respite care services may be available to families through formal programs (i.e., trained staff) or may be available to families through informal networks (e.g., parent cooperatives, or cash subsidies from states to purchase respite through relatives and friends). The following descriptions are examples of local respite care program models.

Model 1: In-Home Respite Program Model

In-home respite programs offer services in the family's home for certain periods of time by trained, paid respite providers or volunteers. Respite programs train providers or volunteers in basic child care areas. Most respite programs interview families and providers and match the two in the provision of respite services; whereas, other respite programs act as "brokers" in which the families choose their own providers from a designated list. In-home respite services provide relief with minimal disruption of routine child care activities. State regulations regarding particular activities (e.g., administration of medications) are followed

(over)

by the respite program. In this type of model, families are usually charged on a sliding fee scale with the respite program paying the provider directly. In many states, families receive a cash subsidy or voucher to pay for in-home respite services.

Model 2: Out-of-Home: Host Family Model

Many respite programs offer services through a host family model in which respite care is provided in a surrogate family home similar to a foster care model. This model allows the child with disabilities to be cared for in a setting outside of his/her natural home. Host family models allow families to receive extended periods of respite. State regulations regarding fire and safety codes, licensing and other requirements must be followed. Most host families are trained by the respite program and paid a daily rate of care. Families are charged on a sliding fee scale for this service.

Model 3: Out-of-Home: Facility-based Model

This type of respite care program is similar to a Mother's Day Out program in which a particular facility (e.g., day care center, church, community center) offers respite on certain days at certain periods of time. This type of model allows families to take their children to a supervised environment. Facility-based respite models are staffed with trained respite providers, paraprofessionals, or volunteers who are able to care for children with certain disabilities. Families are charged for services based on a sliding fee scale. This model is very effective in rural areas.

Model 4: Out-of-Home: Residential Respite Model

In the residential respite model, respite services are provided in a residential or nursing center (e.g., group home, state institution, nursing home, hospital) within a community for individuals with disabilities or terminal illnesses who require skilled care services. Respite, in this model, is conducted by professional licensed personnel, usually for periods longer than 24 hours. Payment for respite services is usually a combination of family fees, state funding (i.e., Medicaid or waiver services), and/or private insurance.

Model 5: Out-of-Home: Respite House Model

In this type of model, a house, specifically designed for the provision of respite care, is available in the community with 24-hour care. Extended respite periods can occur up to 30 days. The respite house model is usually sponsored by a community or state agency and staffed with professional and paraprofessional staff. Families are charged daily rates based on a sliding fee scale. State requirements for food preparation, staff-child ratio, health and safety, and other licensing requirements must be followed.

Model 6: Parent Cooperative Model

Parent cooperatives have been developed in communities, especially rural areas, where respite services are very limited. In this type of model, families of children with disabilities and/or chronic illnesses develop an informal

association and "trade" respite services with each other. This exchange program allows families to receive respite on scheduled dates. In most parent cooperatives, fees are not assessed. This model has proven to be effective for families whose children have similar disabilities. In this regard, families feel comfortable caring for someone else's child who has a disability or illness similar to their own child's.

Model 7: Respite Model

Respite is an innovative concept for providing respite care. It provides a cost-effective partnership between the private sector and respite care agencies. During Respite, participating hotels provided the family with a room, a pleasant dining experience, and perhaps entertainment while a local respite program provides respite either in the family's home or in an out-of-home respite situation. The Respite concept was developed by United Cerebral Palsy-Associations, Inc., in 1985.

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The ARCH National Directory. ARCH National Resource Center, Coordinating Office, Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514; December, 1991.

Resource Centers

Texas Respite Resource Network (TRRN), Santa Rosa Children's Hospital, P.O. Box 7330, San Antonio, Texas 78207-3198; (512) 228-2794

National Information Center for Children and Youth with Handicaps (NICHY), P.O. Box 1492, Washington, DC 20013; 1-800-999-5599

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Respite Care for Children with Developmental and/or Physical Disabilities A Parent's Perspective

Background

Over the past fifteen years, parents have increasingly made the choice to keep their families together. Children with developmental or physical disabilities are no longer routinely placed in institutional care. As a result, the need for respite care (temporary child care) services has increased. Until recently, respite care has been either unavailable or unaffordable in many states. Personal care through the Title XIX Medicaid program and grants through the "Temporary Child Care for Children with Disabilities and Crisis Nurseries Act of 1986" (as amended), have enabled families to receive respite care for free, or at a reduced, reasonable cost. Forty-six states have some form of respite programs for children with disabilities (Knoll, et al., 1990). States and/or agencies that administer respite care projects have realized the need to provide other supports to families which are flexible and meet the need of the whole family, not just the person with a disability. Respite care services form the basis for many state family support programs.

Purpose

For years families caring for a child with medical or physical involvements have been reluctant to allow others to provide care for their child in their own home. The two most common reasons stated by parents are: 1) concerns about the caregiver's training; and 2) feelings that no one can take care of their child as well as they can. Babysitters, in general, do not have the skills needed to provide the kind of support required to care for children with medical or physical disabilities. Respite care programs for families who have children with developmental and/or physical disabilities provide trained respite care providers for in-home or out-of-home "free" time (respite) for families.

Respite Programs

Highlighting the strengths and needs of the entire family, and not just the needs of the individual with a disability, has been a common thread in exemplary programs. Providing respite care for children with developmental or physical

disabilities is not unlike providing respite for any other child. The respite provider needs to know the kinds of behaviors the child is likely to exhibit and be prepared to deal with any unusual needs of the child. This is true of any child. The behaviors and needs of children with disabilities may be more acute, but ascertaining them should be done in the same manner.

For the sake of those programs considering starting a respite program for families with children with developmental or physical disabilities, the following outline is designed to give an idea of the kinds of training and attitudes that are required to provide a quality program.

The Keys to a Successful Respite Program

- Help families feel comfortable and build trust. Spend enough time with the family to develop a level of trust that will allow a free flow of information.
- Provide a flexible structure. The agency should provide as many options as possible to meet the needs of the family, rather than fitting the family into the service available.
- Be family-focused. Empower families to make decisions for themselves. Discuss the strengths and needs of the whole family.
- Provide support. The administering agency and respite care providers must be available to field questions and concerns of parents that may be outside the realm of respite care. This might include linkage and referrals to other agencies or services.
- Allow families to train providers. Be sure to include families in the process of designing the child-specific portion of the provider's training.

Training

Because of the concern that families have about the specialized needs of their children, respite providers should be trained in first aid, CPR, disability awareness issues, specific medical conditions, behavior management, and individual "hands-on" training with the child for whom

they will provide care. Many states and local programs have developed respite training manuals which are available to train local providers. (The ARCH Information Center has copies of many of these manuals.)

Building *trust* is probably the key ingredient in a successful respite program. Training respite workers is only one step in this process. Establishing close working relationships with the family and ensuring close supervision are other important parts of a successful program.

The Basics — These areas can be taught in a classroom setting using professional staff.

- CPR and First Aid
- Philosophy of family empowerment
- "How to speak DD" — introduction to developmental disability terminology
- "Don't Panic" — introduction to medical and environmental emergencies

The Details — These units should be presented in at least two different forums. The first, as a parent panel with discussion of some personal stories in each of the areas mentioned. The second, as a clinical approach to care, to include a speech therapist, an occupational therapist, and a physical therapist.

- Communication sensitivity — how to communicate with someone who does not talk very well, if at all
- Eating etiquette — good table manners (skills) when working with someone who needs assistance
- The comfort factor, or "how would you feel sitting in the same position all day?"

"Hands On" — This section should take place in the families' homes, and/or, the setting where the respite will actually occur.

- Meet the family and get to know the child
- Trainee asks parents about specific assistance he or she may need to provide
- Parents demonstrate how they assist their child to move, eat, and go to the bathroom
- Trainee works with the child on each of the specific skills parents request until parents are comfortable in how the trainee performs

Conclusion

Successful programs from around the country report that, once these key requirements are met, families will enthusiastically participate in respite services. Programs also report that this process takes some time. The trust that families need does not occur overnight. Allow a considerable amount of time for the program to be fully operational.

This can be one of the most rewarding programs to operate. Families and staff report many heartwarming tales of the benefits that respite has provided.

References

Knoll, J., et al. (1990). *Family Support Services in the United States: An End of Decade Status Report*. Cambridge, MA; Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140.

National Commission on Children (1991). *Beyond Rhetoric: a New American Agenda for Children and Families (Summary)*. Washington DC; National Commission on children, 1111 18th Street, N.W., Suite 810, Washington, DC 20036.

Resources

Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, DC 20016. (202) 244-1801. The Association provides information and support on family-centered care for children with special health care needs.

Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140. (617) 876-0426. The Institute has compiled extensive information on respite and other family support services throughout the United States and has numerous documents available.

Family Support Bulletin, produced by United Cerebral Palsy Association, Community Services Division, 1522 K Street, N.W., Suite 1112, Washington, DC 20005. The Bulletin is free of charge and provides excellent information concerning new and upcoming programs nationwide.

Exceptional Parent Magazine, P.O. Box 3000, Dept. EP, Denville, NJ 07834. This is an excellent resource for families and professionals on a wide range of issues concerning children with disabilities.

This fact sheet was developed by Scott Miller, Family Support Services Coordinator for West Virginia. Scott is also the parent of Josh, who has Down's Syndrome.

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National Information Center for Children and Youth with Disabilities

P.O. Box 1492, Washington, D.C. 20013-1492

1-800-695-0285 (Toll Free, Voice/TT)

SpecialNet User Name: NICHCY ** Internet: nichcy@capcon.net

DISABILITIES WHICH QUALIFY CHILDREN AND YOUTH FOR SPECIAL EDUCATION SERVICES UNDER THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

The *Education of the Handicapped Act*, Public Law (P.L.) 94-142, was passed by Congress in 1975 and amended by P.L. 99-457 in 1986 to ensure that children with disabilities would have a free, appropriate public education available to them which would meet their unique needs. It was again amended in 1990, and the name was changed to the *Individuals with Disabilities Education Act* (P.L. 101-476), or IDEA.

IDEA defines "children with disabilities" as having any of following types of disabilities: autism, deaf-blindness, hearing impairments (including deafness), mental retardation, multiple disabilities, orthopedic impairments, other health impairments, serious emotional disturbance, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairments (including blindness). These terms are defined in the regulations for IDEA, as described below.

1. AUTISM

A developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age three, that adversely affects educational performance.

2. DEAFNESS

A hearing impairment which is so severe that a child is impaired in processing linguistic information through hearing, with or without amplification, which adversely affects educational performance.

3. DEAF-BLINDNESS

Simultaneous hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational problems that a child cannot be accommodated in special education programs solely for children with deafness or children with blindness.

4. HEARING IMPAIRMENT

An impairment in hearing, whether permanent or fluctuating, which adversely affects a child's educational performance but which is not included under the definition of "deafness."

5. MENTAL RETARDATION

Significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child's educational performance.

6. MULTIPLE DISABILITIES

Simultaneous impairments (such as mental retardation/blindness, mental retardation/orthopedic impairment, etc.), the combination of which causes such severe educational problems that the child cannot be accommodated in a special education program solely for one of the impairments. The term does not include children with deaf-blindness.

7. ORTHOPEDIC IMPAIRMENT

A severe orthopedic impairment which adversely affects a child's educational performance. The term includes impairments caused by a congenital anomaly (e.g., clubfoot, absence of some limb, etc.), impairments caused by disease (e.g. poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns which cause contractures).

8. OTHER HEALTH IMPAIRMENT

Having limited strength, vitality, or alertness, due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes, which adversely affects a child's educational performance. According to the Office of Special Education and Rehabilitative Services' clarification statement of September 16, 1991, eligible children with ADD may also be classified under "other health impairment."

9. SERIOUS EMOTIONAL DISTURBANCE

(1.) A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance:

(A) an inability to learn which cannot be explained by intellectual, sensory, or health factors; (B) an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; (C) inappropriate types of behavior or feelings under normal circumstances; (D) a general pervasive mood of unhappiness or depression; or (E) a tendency to develop physical symptoms or fears associated with personal or school problems. (II.) The term includes children who have schizophrenia. The term does not include children who are socially maladjusted, unless it is determined that they have a serious emotional disturbance.

10. SPECIFIC LEARNING DISABILITY

A disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems which are primarily the result of visual, hearing, or motor disabilities, of mental retardation, of emotional disturbance, or of environmental, cultural, or economic disadvantage.

11. SPEECH OR LANGUAGE IMPAIRMENT

A communication disorder such as stuttering, impaired articulation, a language impairment, or a voice impairment, which adversely affects a child's educational performance.

12. TRAUMATIC BRAIN INJURY

An acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, which adversely affects educational performance. The term does not include brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

13. VISUAL IMPAIRMENT INCLUDING BLINDNESS

A visual impairment which, even with correction, adversely affects a child's educational performance. The term includes both children with partial sight and those with blindness.

SERVICES FOR INFANTS, TODDLERS, AND PRESCHOOLERS WITH DISABILITIES

P.L. 99-457, the *Education of the Handicapped Act Amendments of 1986*, created a new mandate for all state education agencies to serve all children with disabilities from age three by 1991-1992. The Preschool Program's purpose is to extend the P.L. 94-142 rights to children from age three, including all definitions and requirements. However, Congress made an important distinction for preschoolers: States are not required to label 3-5 year-olds in order to serve these children.

P.L. 99-457 also established the Part H program, now known as the Early Intervention Program for Infants and Toddlers with Disabilities. This program is directed to the needs of children, from birth to their third birthday, who need early intervention services because they: (1) are experiencing developmental delays in one or more of the following areas: cognitive, physical, language and speech, psychosocial, or self-help skills; (2) have a physical or mental condition that has a high probability of resulting in delay, such as Down Syndrome, cerebral palsy, etc.; or (3) at the state's discretion, are at risk medically or environmentally for substantial developmental delays if early intervention is not provided. In addition, under this program the infant or toddler's family may receive services that are needed to help them assist in the development of their child. State definitions of eligibility under this program vary; many states are still in the process of developing their Part H programs. Therefore, depending on the state, services may be fully available or still in the process of developing.

FOR ADDITIONAL INFORMATION

If you feel that any of the above statements accurately describes your child, we encourage you to find out more about special education and related services available in your child's public school district. Many parents have found the NICHCY publication entitled "Questions Parents Often Ask About Special Education Services" helpful. For children birth through 5 years, ask for the publication "A Parents' Guide to Accessing Programs for Infants, Toddlers, and Preschoolers with Disabilities." All NICHCY publications are free of charge.

The Special Education Director for your child's school district, Child Find Coordinator, or the principal of your child's school should be able to answer specific questions you may have about obtaining special education and related services for your child. In addition, the Federally funded Parent Training and Information Programs across the country are excellent sources of information. For a listing of information sources in your state, NICHCY has a State Resource Sheet for each state and U.S. Territory; this sheet includes the address of the Parent Training and Information Program.

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UPDATE 12/93

For more information contact NICHCY.

NICHCY

National Information Center for Children and Youth with Disabilities

P.O. Box 1492, Washington, D.C. 20013-1492

1-800-695-0285 (Toll Free, Voice/TT)

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GENERAL INFORMATION ABOUT PUBLIC AGENCIES

The agencies described below provide assistance to people with disabilities and their families. The *State Resource Sheet* enclosed with this packet will tell you the names and addresses of these agencies in your state. One of the best resources for finding help for your child with a disability is your local school district (sometimes called Local Education Agency). If your child has already begun school and you think your child needs special services, we suggest that you begin by discussing your concerns with your child's teacher or school principal. If your child is an infant, we suggest that you contact the office listed for Programs for Children with Disabilities: Ages Birth through 2 Years. If your child is of preschool age, we suggest that you contact the office listed for Programs for Children with Disabilities: Ages 3 Through 5 Years. These are listed on the *State Resource Sheet* for your state. Ask for the Child Find Coordinator in your community.

STATE EDUCATION DEPARTMENT

The State Department staff can answer questions about special education and related services in your state. Many states have special manuals explaining the steps to take. Check to see if one is available. State Department officials are responsible for special education and related services programs in their state for preschool, elementary and secondary age children.

STATE VOCATIONAL REHABILITATION AGENCY

The state vocational rehabilitation agency provides medical, therapeutic, counseling, education, training and other services needed to prepare people with disabilities for work. This state agency will provide you with the address of the nearest rehabilitation office where you can discuss issues of eligibility and services with a counselor. The state vocational rehabilitation agency can also refer you to an independent living program in your state. Independent living programs provide services which enable adults with disabilities to live productively as members of their communities. The services might include, but are not limited to, information and referral, peer counseling, workshops, attendant care, and technical assistance.

OFFICE OF STATE COORDINATOR OF VOCATIONAL EDUCATION FOR STUDENTS WITH DISABILITIES

States receiving Federal funds used for vocational education must assure that funding is used in programs which include students with disabilities. This office can tell you how your state funds are being used and provide you with information on current programs.

STATE MENTAL RETARDATION/ DEVELOPMENTAL DISABILITIES AGENCIES

The functions of state mental retardation/ developmental disabilities agencies vary from state to state. The general purpose of this office is to plan, administer and develop standards for state/local mental retardation/developmental disabilities programs provided in state-operated facilities and community-based programs. This office provides information about available services to families, consumers, educators and other professionals.

STATE DEVELOPMENTAL DISABILITIES COUNCIL

Assisted by the U.S. Department of Health and Human Services' Administration on Developmental Disabilities, state councils plan and advocate for improvement in services for people with developmental disabilities. In addition, funding is made available for time-limited demonstration and stimulatory grant projects.

STATE MENTAL HEALTH AGENCIES

The functions of state mental health agencies vary from state to state. The general purposes of these offices are to plan, administer, and develop standards for state and local mental health programs such as state hospitals and community health centers. They can provide information to the consumer about mental illness and a resource list of contacts where you can go for help.

PROTECTION AND ADVOCACY AGENCY AND CLIENT ASSISTANCE PROGRAM

Protection and Advocacy systems are responsible for pursuing legal, administrative and other remedies to protect the rights of people who are developmentally disabled or mentally ill, regardless of their age. Protection and Advocacy agencies may provide information about health, residential, and social service in your area. Legal assistance is also available.

The Client Assistance Program provides assistance to individuals seeking and receiving vocational rehabilitation services. These services, provided under the Rehabilitation Act of 1973, include assisting in the pursuit of legal, administrative, and other appropriate remedies to insure the protection of the rights of individuals with developmental disabilities.

PROGRAMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

The U.S. Department of Health and Human Services' Office of Maternal and Child Health and Resource Development provides grants to states for direct medical and related services to children with handicapping conditions. Although services will vary from state to state, additional programs may be funded for training, research, special projects, genetic disease testing, and counseling services. For additional information about current grants and programs in your state, contact the National Center for Education in Maternal and Child Health, 8201 Greensboro Dr., Suite 600, McLean, VA 22102. The telephone number is (703) 821-8955.

UNIVERSITY AFFILIATED PROGRAMS

A national network of programs affiliated with universities and teaching hospitals, UAPs provide interdisciplinary training for professionals and paraprofessionals and offer programs and services for children with disabilities and their families. Some UAPs provide direct services for children and families. Individual UAPs have staff with expertise in a variety of areas and can provide information, technical assistance, and inservice training to agencies, service providers, parent groups, and others.

You can obtain a listing of all University Affiliated Programs by contacting The Maternal and Child Health Clearinghouse, 8201 Greensboro Dr., Suite 600, McLean, VA 22102. The telephone number is (703) 821-8955. Additional information about UAPs may be obtained by contacting:

American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP)

8630 Fenton Street, Suite 410
Silver Spring, MD 20910
(301) 588-8252

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NICHCY

National Information Center for Children and Youth with Disabilities

P.O. Box 1492, Washington, D.C. 20013-1492

1-800-695-0285 (Toll Free, Voice/TT)

*SpecialNet User Name: NICHCY ** Internet: nichcy@capcon.net*

NATIONAL RESOURCES

CLEARINGHOUSES

Clearinghouse on Disability Information
Office of Special Education and Rehabilitative
Services

Room 3132, Switzer Building
330 C Street S.W.
Washington, DC 20202-2524
(202) 205-8241 (Voice/TT)

DB-LINK

National Information Clearinghouse on Children
Who Are Deaf-Blind
345 N. Monmouth Avenue
Monmouth, OR 97361
(800) 438-9376
(800) 854-7013 (TTY)

ERIC Clearinghouse on Disabilities and Gifted
Education

Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 22091-1589
(703) 620-3660
(800) 328-0272

HEATH Resource Center (National Clearinghouse
on Postsecondary Education for Individuals with
Disabilities)

One Dupont Circle, N.W., Suite 800
Washington, D.C. 20036-1193
(202) 939-9320; (800) 544-3284 (Voice/TT)

National Clearinghouse for Professions in Special
Education

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091-1589
(703) 264-9474

National Clearinghouse on Family Support and
Children's Mental Health

Portland State University
P.O. Box 751
Portland, OR 97207-0751
(800) 628-1696
(503) 725-4040
(503) 725-4165 (TT)

National Health Information Center

P.O. Box 1133
Washington, D.C. 20013-1133
(301) 565-4167
(800) 336-4797

National Information Center on Deafness (NICD)

800 Florida Avenue, N.E.
Washington, D.C. 20002
(202) 651-5051 (Voice)
(202) 651-5052 (TT)

Publications available in Spanish

National Information Clearinghouse (NIC) for
Infants with Disabilities and Life-Threatening
Conditions

Center for Developmental Disabilities
University of South Carolina
Columbia, SC 29208
(800) 922-9234, ext. 201 (Voice/TT)

National Information System for Vietnam
Veterans and Their Families

Center for Developmental Disabilities
Columbia, SC 29208
(800) 922-9234, ext. 401 (Voice/TT)

National Maternal and Child Health Clearinghouse

8201 Greensboro Dr., Suite 600
McLean, VA 22102
(703) 821-8955 Ext. 254 or 265
Publications available in Spanish
Spanish speaker on staff

National Organization for Rare Disorders (NORD)

100 Route 37
P.O. Box 8923
New Fairfield, CT 06812-1783
(800) 999-6673
(203) 746-6518
(203) 746-6927 (TT)

National Rehabilitation Information Center
(NARIC)

8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319
(301) 588-9284
(800) 346-2742, ext. 22 (Voice/TT)
Spanish speaker on staff

ORGANIZATIONS

Alliance for Technology Access
2173 East Francisco Boulevard, Suite L
San Rafael, CA 94901
(415) 455-4575

Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440
Chevy Chase, MD 20815
(800) 336-4363
(301) 652-5553

American Council of Rural Special Education
(ACRES)
Department of Special Education
University of Utah
Milton Bennion Hall, Room 221
Salt Lake City, UT 84112
(801) 581-8442

American Foundation for the Blind (AFB)
11 Penn Plaza, Suite 300
New York, NY 10001
(800) 232-5463 (Voice)
(212) 502-7600 (Voice)
(212) 502-7662 (TT)
Publications available in Spanish

American Occupational Therapy Association
(AOTA)
4720 Montgomery Lane
P.O.Box 31220
Bethesda, MD 20824-1220
(301) 652-2682
(800) 377-8555 (TT)

American Physical Therapy Association (APTA)
1111 North Fairfax Street
Alexandria, VA 22314
(703) 684-2782
(800) 999-2782

American Speech-Language-Hearing Association
(ASHA)
10801 Rockville Pike
Rockville, MD 20852
(301) 897-5700 (Voice/TT)
(800) 638-8255

Association for the Advancement of Rehabilitation
Technology (RESNA)
1700 N. Moore Street, Suite 1540
Arlington, VA 22209-1903
(703) 524-6686 (Voice)
(703) 524-6639 (TT)

Association for the Care of Children's Health
(ACCH)
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3015
(301) 654-6549

Association for Persons with Severe Handicaps
(TASH)
29 W. Susquehanna Ave., Suite 210
Baltimore, MD 21204
(410) 828-8274
Spanish speaker on staff

The Arc (formerly the Association for Retarded
Citizens of the U.S.)
500 E. Border Street, Suite 300
Arlington, TX 76010
(817) 261-6003
(817) 277-0553 (TT)
(800) 433-5255

Autism Society of America (formerly NSAC)
7910 Woodmont Avenue, Suite 650
Bethesda, MD 20814
(301) 657-0881
(800) 3-AUTISM
Fact sheet available in Spanish

Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Disability Statistics Research and Training Center
Institute for Health and Aging
University of California, San Francisco
Box 0646
San Francisco, CA 94143-0646
(415) 502-5210 (Voice/TT)

Epilepsy Foundation of America (EFA)
4351 Garden City Drive, 5th Floor
Landover, MD 20785
(301) 459-3700
(800) 332-1000
Publications available in Spanish
Spanish speaker on staff

Family Resource Center on Disabilities
20 East Jackson Boulevard, Room 900
Chicago, IL 60604
(800) 952-4199 (in IL only)
(312) 939-3513
(312) 939-3519 (TT)

Head Start Bureau
Administration on Children, Youth and Families
U.S. Department of Health & Human Services
P.O. Box 1182
Washington, D.C. 20013
(202) 205-8347

Independent Living Research Utilization Project (ILRU)
The Institute for Rehabilitation and Research
2323 South Sheppard, Suite 1000
Houston, TX 77019
(713) 520-0232
(713) 520-5136 (TT)

International Rett Syndrome Association
9121 Piscataway Rd., Suite 2B
Clinton, MD 20735
(301) 856-3334
Publication "What is Rhett Syndrome?" available in Spanish

Learning Disability Association of America (LDA)
(formerly ACLD)
4156 Library Road
Pittsburgh, PA 15234
(412) 341-1515
(412) 341-8077
Publications available in Spanish

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100
Publications available in Spanish
Spanish speaker on staff

Muscular Dystrophy Association (MDA)
3300 East Sunrise Drive
Tucson, AZ 85718
(602) 529-2000
Publications available in Spanish
Spanish speaker on staff

National Alliance for the Mentally Ill (NAMI)
200 N. Glebe Rd., Suite 1015
Arlington, VA 22203-3754
(703) 524-7600
(800) 950-NAMI

National Association of Private Schools for Exceptional Children (NAPSEC)
1522 K Street N.W., Suite 1032
Washington, DC 20005
(202) 408-3338

National Association of Protection and Advocacy Systems (NAPAS)
900 Second Street N.E., Suite 211
Washington, DC 20002
(202) 408-9514 (Voice)
(202) 408-9521 (TT)

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
(800) 232-6372 (Toll-free)
(404) 633-1555
Pamphlet available in Spanish
Spanish speaker on staff

National Down Syndrome Society
666 Broadway
New York, NY 10012
(212) 460-9330
(800) 221-4602
Publications available in Spanish
Spanish speaker on staff

National Easter Seal Society, Inc.
230 West Monroe Street, Suite 1800
Chicago, IL 60606
(312) 726-6200
(312) 726-4258 (TT)
(800) 221-6827
Publications available in Spanish
Spanish speaker on staff

National Fragile X Foundation
1441 York Street, Suite 303
Denver, CO 80206
(303) 333-6155
(800) 688-8765

National Head Injury Foundation, Inc.
1776 Massachusetts Ave., N.W., Suite 100
Washington, D.C. 20036
(202) 296-6443
Publications available in Spanish

National Library Services for the Blind & Physically Handicapped
The Library of Congress
Washington, D.C. 20542
(202) 707-5100
(800) 424-8567
(800) 424-9100 (TT, English)
(800) 345-8901 (TT, Spanish)

National Spinal Cord Injury Association
545 Concord Avenue
Cambridge, MA 02138
(617) 441-8500
(800) 962-9629
Publications available in Spanish
Spanish speaker on staff

Orton Dyslexia Society
Chester Building # 382
8600 LaSalle Road
Baltimore, MD 21286
(410) 296-0232
(800) 222-3123
Pamphlet available in Spanish

Parents Helping Parents:
The Parent-Directed Family Resource Center
for Children with Special Needs
3041 Olcott St.
Santa Clara, CA 95054
(408) 727-5775
Publications available in Spanish
Spanish speaker on staff

President's Committee's Job Accommodation
Network
West Virginia University
918 Chestnut Ridge Road, Suite 1
P.O. Box 6080
Morgantown, WV 26506-6080
(800) 526-7234 (Voice/TT)
(800) 232-9675 (Voice/TT)
(800) 526-2262 (Voice/TT, toll-free in Canada)

Recording for the Blind
The Anne T. Macdonald Center
20 Roszel Road
Princeton, NJ 08540
(800) 221-4792
(609) 452-0606

Sibling Information Network
A.J. Pappanikou Center
62 Washington Street
Middletown, CT 06475
(203) 344-7500
Spanish speaker on staff

Sick Kids (need) Involved People (SKIP)
545 Madison Avenue, 13th Floor
New York, NY 10022
(212) 421-9160
(212) 421-9161
Spanish speaker on staff

Special Olympics
1325 G Street N.W., Suite 500
Washington, D.C. 20005
(202) 628-3630
Publications available in Spanish and French
Spanish - French speaker on staff

Spina Bifida Association of America
4590 MacArthur Boulevard, N.W., Suite 250
Washington, D.C. 20007
(202) 944-3285
(800) 621-3141
Publications available in Spanish

Technical Assistance to Parent Programs (TAPP)
Network
Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, MA 02116
(617) 482-2915
(800) 331-0688 (in MA only)
Spanish speaker on staff

Trace Research & Development Center
S-151 Waisman Center, 1500 Highland Avenue
University of Wisconsin-Madison
Madison, WI 53705-2280
(608) 262-6966
(608) 262-5408 (TT)

United Cerebral Palsy Association, Inc.
1660 L Street, N.W., Suite 700
Washington, DC 20036
(202) 842-1266
(800) 872-5827

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NICHCY

National Information Center for Children and Youth with Disabilities

P.O. Box 1492, Washington, D.C. 20013-1492

1-800-695-0285 (Toll Free, Voice/TT)

*SpecialNet User Name: NICHCY ** Internet: nichcy@capcon.net*

NATIONAL TOLL FREE NUMBERS

The following is a selected list of toll-free numbers for national organizations concerned with disability and children's issues. Inclusion on this list does not imply endorsement by NICHCY or the Office of Special Education Programs. There are also many national disability organizations providing services and information which do not have toll-free numbers. If you would like additional help in locating assistance contact NICHCY at 1-800-695-0285 (Voice/TT).

Note: Telephone numbers are designated either Voice (V) or Text Telephone (TT), indicating their accessibility to TT users. Spanish-language resources are also indicated.

AIDS

CDC National AIDS Clearinghouse
1(800) 458-5231 (V; English/Spanish)
1(800) 243-7012 (TT)

CDC National AIDS Hotline
1(800) 342-2437 (V)
1(800) 344-7432 (V; Spanish)
1(800) 243-7889 (TT)

Hemophilia and AIDS/HIV Network for
Dissemination of Information
1(800) 424-2634 (V)

ALCOHOL AND OTHER DRUG ABUSE
National Institute on Drug Abuse Helpline
1(800) 662-4357 (V)

OSAP National Clearinghouse for Alcohol and Drug
Information
1(800) 729-6686 (V)
1(800) 487-4889 (TT)

AMERICANS WITH DISABILITIES ACT (ADA)
Disability Rights Education and Defense Fund
ADA Technical Assistance Information Line
1(800) 466-4232 (V/TT)

Equal Employment Opportunity Commission
1(800) 669-3362 (V)
1(800) 800-3302 (TT)

Job Accommodation Network
1(800) 526-7234 (V/TT)
1(800) 232-9675 (V/TT; ADA Information)

U.S. Architectural and Transportation Barriers
Compliance Board -- Access Board
1(800) 872-2253 (V)
(202) 728-5483 (TT)

U.S. Department Of Housing and Urban
Development -- HUD User
1(800) 245-2691 (V)

ASSISTIVE TECHNOLOGY/DEVICES

AbleNet
1(800) 322-0956 (V)

Apple Office for Special Education Material
1(800) 732-3131, ext. 950 (V)

AT&T Accessible Communications Product Center
1(800) 233-1222 (V)
1(800) 833-3232 (TT)

IBM Special Needs Information Referral Center
1(800) 426-4832 (V)
1(800) 284-4833 (TT)

TECHKNOWLEDGE

1(800) 726-9119
(404) 894-4960 (V; Atlanta Metro Area)

BLINDNESS/VISUAL IMPAIRMENTS

American Council of the Blind
1(800) 424-8666 (V/TT)

American Foundation for the Blind
1(800) 232-5463 (V)

Blind Children's Center
1(800) 222-3566 (V)
1(800) 222-3567 (V; in CA)

Hadley School for the Blind
1(800) 323-4238 (V)

Job Opportunities for the Blind
1(800) 638-7518 (V)
(410) 659-9314 (V; in MD)

Lighthouse National Center for Vision and Child Development
1(800) 334-5497 (V)
(212) 808-5544 (TT)

National Association of Parents of the Visually Impaired
1(800) 562-6265 (V)

National Society to Prevent Blindness
1(800) 331-2020 (V)

Recording for the Blind
1(800) 221-4792 (V)

Retinitis Pigmentosa Foundation
1(800) 683-5555 (V)
(410) 225-9400 (V; in MD)
(410) 225-9409 (TT)

BURNS
Phoenix Society
1(800) 888-2876 (V)

CANCER
Cancer Information and Counseling Line
1(800) 525-3777 (V)

Candlelighters Childhood Cancer Foundation
1(800) 366-2223 (V)

National Cancer Information Service
1(800) 422-6237 (V; English/Spanish)

CHILD ABUSE

Clearinghouse on Child Abuse and Neglect/Family Violence Information
1(800) 394-3366 (V)

National Resource Center on Child Sexual Abuse
1(800) 543-7006 (V)

COMMUNICATION DISORDERS

National Institute on Deafness and Other Communication Disorders Clearinghouse
1(800) 241-1044 (V)
1(800) 241-1055 (TT)

CRANIOFACIAL SYNDROMES

Children's Craniofacial Association
1(800) 535-3643 (V)

FACES -- National Association for the Craniofacially Handicapped
1(800) 332-2373 (V)

National Foundation for Facial Reconstruction
1(800) 422-3223

DEAFNESS/HEARING IMPAIRMENTS

American Society for Deaf Children
1(800) 942-2732 (V/TT)

Better Hearing Institute
1(800) 327-9355 (V/TT)

Deafness Research Foundation
1(800) 535-3323 (V/TT)
(212) 684-6559 (V/TT; in NY)

Hear Now
1(800) 648-4327 (V/TT)

John Tracy Clinic
1(800) 522-4582 (V/TT)
(213) 748-5481 (V; in 213 area)
(213) 747-2924 (TT; in 213 area)

National Hearing Aid Society
1(800) 521-5247 (V)

National Institute on Deafness and Other Communication Disorders Clearinghouse
1(800) 241-1044 (V)
1(800) 241-1055 (TT)

MEDICAL/HEALTH DISORDERS

American Association of Kidney Patients

1(800) 749-2257 (V)

American Brain Tumor Association

1(800) 886-2282 (V)

American Diabetes Association

1(800) 582-8323 (V)

American Kidney Fund

1(800) 638-8299 (V)

American Liver Foundation

1(800) 223-0179 (V)

American Lupus Society

1(800) 331-1802 (V)

Asthma and Allergy Foundation of America

1(800) 727-8462 (V)

Chronic Fatigue and Immune Dysfunction Syndrome Association

1(800) 442-3437 (V)

Federal Hill-Burton Free Hospital Care Program

1(800) 638-0742 (V)

1(800) 492-0359 (V; in MD)

Leukemia Society of America

1(800) 955-4572 (V)

Lupus Foundation of America

1(800) 558-0121 (V)

1(800) 558-0231 (V; Spanish)

National Association for Sickle Cell Disease

1(800) 421-8453 (V)

Shriners Hospital for Crippled Children

1(800) 237-5055 (V)

1(800) 282-9161 (V; in FL)

United Ostomy Association

1(800) 826-0826 (V)

MENTAL HEALTH

National Alliance for the Mentally Ill

1(800) 950-6264 (V)

National Clearinghouse on Family Support and Children's Mental Health

1(800) 628-1696 (V)

National Mental Health Association

1(800) 969-6642 (V)

MENTAL RETARDATION

American Association on Mental Retardation

1(800) 424-3688 (V)

The Arc

1(800) 433-5255 (V)

NUTRITION

Beech-Nut Nutrition Hotline

1(800) 523-6633 (V)

Gerber Consumer Information

1(800) 443-7237 (V)

PHYSICAL DISABILITIES

American Paralysis Association

1(800) 526-3456 (V)

Human Growth Foundation

1(800) 451-6434 (V)

Physically Challenged Resource Center

1(800) 255-9877 (V)

RARE SYNDROMES

Alliance of Genetic Support Groups

1(800) 336-4363 (V)

National Information Center on Orphan Drugs and Rare Diseases

1(800) 456-3505 (V)

National Organization for Rare Disorders

1(800) 999-6673 (V/TT)

RECREATION

Adventures in Movement for the Handicapped, Inc.

1(800) 332-8210 (V)

Magic Foundation

1(800) 362-4423 (V)

TRIPOD (Information for parents of deaf children)

1(800) 352-8888 (V/TT)

1(800) 346-8888 (V/TT; in CA)

DISABILITY AWARENESS

Kids on the Block

1(800) 368-5437

EDUCATION

American Association for Vocational Instructional Materials

1(800) 228-4689 (V)

Association for Childhood Education International

1(800) 423-3563 (V)

HEATH Resource Center

1(800) 544-3284 (V/TT)

(202) 939-9320 (V/TT; in DC)

National Center for Research in Vocational Education

1(800) 762-4093 (V)

National Center for School Leadership

1(800) 643-3205 (V)

National Committee for Citizens in Education
Clearinghouse

1(800) 638-9675 (V)

1(800) 532-9832 (V; Spanish)

U.S. Office of Educational Research and Improvement

1(800) 424-1616 (V)

EMPLOYMENT

Equal Employment Opportunity Commission

1(800) 669-3362 (V)

1(800) 800-3302 (TT)

Job Accommodation Network

1(800) 526-7234 (V/TT)

1(800) 232-9675 (V/TT; ADA Information)

Job Opportunities for the Blind

1(800) 638-7518 (V)

(410) 659-9314 (V; in MD)

FINANCIAL COUNSELING

National Foundation for Consumer Credit

1(800) 388-2227 (V)

HOSPICE

Children's Hospice International

1(800) 242-4453 (V/TT)

HOSPICELINK

1(800) 331-1620

(203) 767-1620 (V; in CT)

INFORMATION SERVICES

ABLEDATA/National Rehabilitation Information
Clearinghouse

1(800) 346-2742 (V/TT)

ACCESS ERIC

1(800) 538-3742 (V)

BRS Information Technologies

1(800) 289-4277 (V)

National Center for Youth with Disabilities

1(800) 333-6293 (V)

(612) 624-3939 (TT)

National Easter Seal Society

1(800) 221-6827 (V)

(312) 726-4258 (TT)

National Information Clearinghouse for Infants with
Disabilities and Life Threatening Conditions

1(800) 922-9234, ext. 201 (V/TT)

1(800) 922-1107, ext. 201 (V/TT; in SC)

ODPHP National Health Information Center

1(800) 336-4797 (V)

Office of Minority Health Resource Center

1(800) 444-6472 (V)

LITERACY

National Literacy Hotline

1(800) 228-8813 (V)

1(800) 552-9097 (TT)

North American Riding for the Handicapped, Inc.
1(800) 369-7433 (V)

Sunshine Foundation
1(800) 767-1976 (V)

REHABILITATION

Clearinghouse for Rehabilitation and Technology Information
1(800) 638-8864 (V)
1(800) 852-2892 (TT)

National Clearinghouse of Rehabilitation Training Materials
1(800) 223-5219 (V/TT)

National Rehabilitation Information Clearinghouse/
ABLEDATA
1(800) 346-2742 (V/TT)

RESPIRATORY DISORDERS

National Jewish Center for Immunology and Respiratory Medicine -- LUNGLINE
1(800) 222-5864 (V)

RESPITE CARE

Access to Respite Care and Help (ARCH) National Resource Center
1(800) 473-1727 (V)

RURAL

ERIC Clearinghouse on Rural Education and Small Schools
1(800) 624-9120 (V)
1(800) 344-6646 (V; in WV)

Rural Institute on Disabilities (Montana University Affiliated Program)
1(800) 732-0323 (V/TT)

SPECIFIC DISABILITIES

Attention Deficit Disorder Association
1(800) 487-2282 (V)

Cleft Palate Foundation
1(800) 242-5338 (V)

Cooley's Anemia Foundation
1(800) 221-3571 (V)
1(800) 522-7222 (V; in NY)

Cornelia de Lange Syndrome Foundation
1(800) 223-8355 (V)
1(800) 753-2357 (V; in CT)

Cystic Fibrosis Foundation
1(800) 344-4823 (V)

Epilepsy Foundation of America
1(800) 332-1000 (V)

Little People of America
1(800) 243-9273 (V)

National Down Syndrome Congress
1(800) 232-6372 (V)

National Down Syndrome Society
1(800) 221-4602 (V)

National Fragile X Foundation
1(800) 688-8765 (V)

National Multiple Sclerosis Society
1(800) 532-7667 (V)

National Organization for Albinism and Hypopigmentation
1(800) 473-2310 (V)

National Reye's Syndrome Foundation
1(800) 233-7393 (V)

National Tuberous Sclerosis Association
1(800) 225-6872 (V)

Orton Dyslexia Society
1(800) 222-3123 (V)

Prader-Willi Syndrome Association
1(800) 926-4797 (V)

Spina Bifida Associations of America
1(800) 621-3141 (V)

Stuttering Foundation of America
1(800) 992-9392 (V)

Sudden Infant Death Syndrome Alliance
1(800) 221-7437 (V)

Tourette Syndrome Association
1(800) 237-0717 (V)

United Cerebral Palsy Associations
1(800) 872-5827 (V/TT)

United Leukodystrophy Foundation
1(800) 728-5483 (V)

United Scleroderma Foundation
1(800) 722-4673 (V)

SUPPLEMENTAL SECURITY INCOME (SSI)

Social Security Administration
1(800) 772-1213 (V)
1(800) 325-0778 (TT)
1(800) 392-0812 (TT; in MO)

Zebley Implementation Project
1(800) 523-0000 (V)
(215) 893-5356 (V; Philadelphia Metro Area)

TRAUMA

American Trauma Society
1(800) 556-7890 (V)

National Head Injury Foundation
1(800) 444-6443 (V)

National Spinal Cord Injury Association
1(800) 962-9629 (V)

VIETNAM VETERANS/AGENT ORANGE

Access Group for Children of Vietnam Veterans
1(800) 821-8580 (V)

National Information System for Vietnam Veterans and
Their Families

1(800) 922-9234, ext. 401 (V/TT)
1(800) 922-1107, ext. 401 (V/TT; in SC)

BEST COPY AVAILABLE

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UPDATE 6A



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Send information in: ☐ English ☐ Spanish

GENERAL RESOURCE

- ☐ GR1 Brochure *
- ☐ GR2 National Resources
- ☐ GR3 General Information about Disabilities *
- ☐ GR4 Public Agencies Fact Sheet
- ☐ GR5 National Toll Free Numbers
- ☐ GR6 State Resource Sheet: State
- ☐ GR8 Publications List

NEWS DIGEST

- ☐ ND11 Children with Disabilities: Understanding Sibling Issues
- ☐ ND12 Respite Care: A Gift of Time
- ☐ ND13 Assistive Technology: Becoming an Informed Consumer
- ☐ ND14 Having a Daughter with a Disability: Is it Different for Girls?
- ☐ ND15 Education of Children & Youth With Special Needs: What Do the Laws Say? (Vol. I, No. 1, 1991)
- ☐ ND16 Related Services for School-aged Children with Disabilities (Vol. I, No. 2, 1991)
- ☐ ND17 Sexuality Education for Children and Youth with Disabilities (Vol. I, No. 3, 1992)
- ☐ ND18 Estate Planning (Vol. II, No. 1, 1992)
- ☐ ND19 Promising Practices & Future Trends for Special Education (Vol. II, No. 2, 1993)
- ☐ ND20 Parenting a Child with Special Needs: Guide to Readings and Resources (Vol. III, No. 1, 1993)
- ☐ ND21 Questions & Answers about the Individuals with Disabilities Education Act (Vol. III, No. 2, 1993)*
- ☐ ND22 Directory of Organizations (Vol. III, No. 3, 1993)
- ☐ ND23 Assessing Children for the Presence of a Disability (Vol. IV, No. 1, 1994)

TRANSITION SUMMARY

- ☐ TS8 Transition Services in the IEP

DISABILITY INFORMATION

- ☐ FS1 Autism *
- ☐ FS2 Cerebral Palsy *
- ☐ FS3 Deafness *
- ☐ FS4 Down Syndrome *
- ☐ FS5 Emotional Disturbance *

- ☐ FS6 Epilepsy *
- ☐ FS7 Learning Disabilities *
- ☐ FS8 Mental Retardation *
- ☐ FS10 Severe and/or Multiple Disabilities
- ☐ FS11 Speech and Language Impairments
- ☐ FS12 Spina Bifida *
- ☐ FS13 Visual Impairments *
- ☐ FS14 Attention Deficit Disorder (Briefing Paper)
- ☐ FS17 Reading and Learning Disabilities Resource Guide
- ☐ FS18 Traumatic Brain Injury *

MATERIALS FOR PARENTS

- ☐ PA2 Parent's Guide to Accessing Programs for Infants, Toddlers, Preschoolers w/Disabilities (ages 0-5) *
- ☐ PA6 Parent's Guide: Accessing the ERIC Resource Collection
- ☐ PA7 Parent's Guide to Doctors, Disabilities, and the Family
- ☐ PA8 Parent's Guide: Planning a Move, Mapping Your Strategy
- ☐ PA9 Parent's Guide: Special Education and Related Services: Communicating Through Letter Writing (Vol. II, No. 1, Sept. 1991)*
- ☐ PA10 Parent's Guide: Accessing Parent Groups*

BIBLIOGRAPHIES

- ☐ B1 Assessing Children for the Presence of a Disability: Schools
- ☐ B2 Assessing Children for the Presence of a Disability: Families
- ☐ B3 Behavior Management: Schools
- ☐ B4 Behavior Management: Families
- ☐ B5 Children's Literature
- ☐ B6 Mental Health/Mental Illness: Schools
- ☐ B7 Mental Health/Mental Illness: Families

OTHER

- ☐ PAY Paying the Medical Bills
- ☐ ADT Resources for Adults with Disabilities
- ☐ LG1 Questions Often Asked About Special Education Services (ages 3-21) *
- ☐ LG2 Individualized Education Programs (IEPs)
- ☐ TA1 Technical Assistance Guide: Operating a Local Information and Referral Center

Please complete the following:

What age ranges are you interested in? (Please circle all ages that apply)

0-2 3-5 6-12 13-18

19-22 23-over All ages

Have you contacted NICHCY before?

☐ Yes ☐ No

Check the one that best describes you:

- ☐ Parent/Family Member
- ☐ Educational Professional
- ☐ Other Professional
- ☐ Advocate
- ☐ Adult with Disabilities
- ☐ Student with Disabilities
- ☐ Student without Disabilities
- ☐ Parent Organization/Group
- ☐ Library/Information Center
- ☐ Other (Please specify _____)

PLEASE TYPE OR PRINT CLEARLY.

First Name

Last Name

Organization (for mailing list purposes only)

Address

City

State

Zip Code

Daytime Telephone
(Area Code + Number)

The National Information Center for Children and Youth with Disabilities (NICHCY) is a national information and referral clearinghouse. We operate through the Clearinghouse Program authorized by Section 633 of Part D of the Individuals with Disabilities Education Act (20 U.S.C. 1433), as amended by Public Law 101-476.

AED •

Academy for Educational Development

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Section 10

forms for sharing
information

Sharing Information with Caregivers

Information Worksheets

There are a variety of forms available in this section for families to use in sharing important information with caregivers. Families can use these forms as needed. Some forms provide information specific to the child with special needs and other forms are specific to the needs of siblings also in care. Some forms provide space to include other family and household information. Emergency, health, and safety information sheets and checklists are helpful for caregivers to have.

Master copies of all forms and worksheets are included in this section. Families can make copies of forms that several caregivers may need. Families may also keep blank copies and use them when changes occur or new information becomes available.



Essential Information

General Information

Child's Name: _____ Nickname: _____

Address: _____

Phone: _____ Allergies: _____

Age: _____ D.O.B. _____ Height: _____ Weight: _____

Child diagnosis or description of special needs: _____

Health Insurance: _____ I.D. Number: _____

You can reach me at _____

If you cannot contact me, please call:

_____ Phone: _____

Medication

Name of medication: _____

Purpose for medication: _____

Time to be given: _____ Dosage: _____

Pharmacy: _____ Phone: _____

Comments: _____



Essential Information (continued)

Food

Allergies: _____

Cannot have: _____

Acceptable snacks: _____

Meals: _____

Daily Schedule

AM: _____

PM: _____

Nap Time: _____



Health and Medical Information

Child's Name: _____ Date of Birth: _____

Current Health Problems / Needs: _____

Allergies (if any): _____

Child's Physician: _____

Address: _____

Phone: _____

Name and Number of Medical Insurance: _____

Authorization for Emergency Medical Care

_____ has permission to obtain immediate medical care for my child if any emergency occurs when the parent or guardian cannot be located. I understand the child's physician will be contacted if available.

Parent or Guardian: _____ Date: _____



Important Phone Numbers

Mother's Work: _____

Father's Work: _____

Police/Emergency: _____

Fire/Emergency: _____

Poison Control: _____

Doctor's Office: _____

Pharmacy: _____

Hospital: _____

Dentist: _____

Neighbor/Friend: _____

Neighbor/Friend: _____

Relative: _____

Relative: _____

Gas Company: _____

Electric Company: _____

Phone Company: _____

Apartment Manager: _____

Veterinarian: _____

Other: _____



About My Child

Child's Name: _____ Date: _____

What I would like to tell you about my child: _____

Favorite toys or playthings: _____

Special routines (a good-bye hug, snack after school, story for bedtime, etc.)

my child enjoys: _____

Special things (blanket, a pacifier, stuffed animal, etc.) that my child enjoys:

Things that scare my child: _____



Things that quiet or comfort my child: _____

Special things my child does: _____

Activities my child likes: _____

Activities my child dislikes: _____

Personality or behavior style (such as active, quiet, silly, serious): _____

Things that are easy for my child: _____

Things that are hard for my child: _____

Special names or words for people or things that my child understands/uses:

Other special information or concerns: _____

About Our Family

The people in our family are: _____

Some things our family does together: _____

Special things each member of my family does alone or with someone else:

Things we would like to do if we had respite: _____



Dreams for our child with disabilities: _____

Dreams for our family: _____



About Sisters and Brothers

General Information

Brother/Sister's Name: _____ Nickname: _____

Age: _____ D.O.B.: _____ Height: _____ Weight: _____

Allergies: _____

Important health or developmental history: _____

Medications

Name of medication: _____

Purpose for medication: _____

Time to be given: _____ Dosage: _____

Pharmacy: _____ Phone: _____

Prescribing Doctor: _____

Doctor's Phone: _____

Let me tell you about _____



Let me tell you about _____

This image shows a single page of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There is no handwriting or printed text on the page.

Health and Safety Checklist

Our caregiver is certified in:

- ☐ infant/child CPR
- ☐ first aid

Our caregiver knows where we keep our:

- ☐ medical treatment release forms
- ☐ medical insurance information
- ☐ first-aid kit and book
- ☐ sunscreen

We have provided our caregiver individualized training on:

- ☐ emergency plans
 - ☐ what we would consider an emergency for our child
 - ☐ what we would like our caregiver to do in case of an emergency
 - ☐ where we keep emergency phone numbers
- ☐ fire safety
 - ☐ location of and how to use the fire extinguisher
 - ☐ our fire evacuation plan
 - ☐ location of smoke detector
- ☐ poison safety
 - ☐ where we keep the Poison Control Center phone number
 - ☐ where we keep the Syrup of Ipecac
- ☐ kitchen safety (i.e., stove, appliances, pots on the stove, etc.)
 - ☐ first aid for burns



We have provided our caregiver individualized training on:

- ☐ hand washing for caregivers and children after toileting and outside time and before food preparation
- ☐ medication administration
- ☐ our smoking policy
- ☐ diaper/toileting routine and diaper disposal
- ☐ toy safety (e.g., balloons might suffocate small children, young children might choke on small toys or toys with small parts)
- ☐ use of medical equipment
- ☐ crib/bed safety
 - ☐ young children should sleep on their backs
 - ☐ the side rail of a crib should be latched when the child is asleep
 - ☐ caregivers should check on sleeping children
 - ☐ bottles should be held and not propped for young children
- ☐ positioning, exercises, and therapeutic activities
- ☐ car safety
 - ☐ car seats are available and adjusted for our child
 - ☐ correct use of a car seat
 - ☐ child should always be in a car seat or fastened seat belt when the car moving
- ☐ my child's allergies
 - ☐ medical care if my child is exposed to allergens
- ☐ safety in the home
 - ☐ electrical outlets are covered
 - ☐ hot water heater adjusted to 120 degrees or lower
 - ☐ guns are unloaded and locked in a cabinet
 - ☐ bullets are locked in cabinets separate from guns
- ☐ medications, poisonous chemicals, and liquor are kept out of the reach of children
- ☐ rubber mats or nonslip surfaces are in showers or tubs children will use



Step 1: Identify training goals.

What do you want your caregiver to learn about your child and family routines?

I want my caregiver to learn about these routines:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____



Step 2: List training methods.

What methods will you use to teach your caregivers?

In order to reach these goals I will use the following methods:

Goal 1: _____

Methods:

1. _____

2. _____

3. _____

Goal 2: _____

Methods:

1. _____

2. _____

3. _____



Goal 3: _____

Methods:

1. _____

2. _____

3. _____

Goal 4: _____

Methods:

1. _____

2. _____

3. _____

Goal 5: _____

Methods:

1. _____

2. _____

3. _____



Step 3:

Use resources to help train your caregiver.

What information will you use to help your caregiver learn?

These are the resources I would like to use:

- ☐ books
- ☐ handouts
- ☐ videotapes
- ☐ audiotapes
- ☐ computer search
- ☐ I develop resources
- ☐ other (please describe)



Step 4: Evaluation

How will you and your caregiver know when a specific skill or routine has been learned?

I will know a specific skill or routine has been learned when we accomplish the following:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____



Personalized Training Plan

Child's Name: _____ Date: _____

Routine: _____

Time of Day: _____

Step 1: Training Goal _____

Step 2: Training Methods _____

Step 3: Resources _____

Step 4: Evaluation _____



Respite Caregiver Profile

Date: _____

Personal:

Name: _____ SS#: _____

Address: _____

Home Telephone: _____ Work Telephone: _____

In case of emergency, notify: _____

Relationship: _____

Home Telephone: _____ Work Telephone: _____

Experience:

Describe experience you have had with children (including your own). _____

Have you ever provided care for children with disabilities?

☐ Yes ☐ No

If yes, please list your experiences: _____



Respite Caregiver Profile, continued

Have you had any courses in early childhood, child development, or child health?

☐ Yes ☐ No

Are you certified in Red Cross First Aid?

☐ Yes ☐ No Date of Expiration _____

Are you certified in Infant/Child CPR?

☐ Yes ☐ No Date of Expiration _____

Do you have a valid driver's license?

☐ Yes ☐ No Date of Expiration _____

Education:

I have completed:

High School _____ Some College _____

College _____ Graduate School _____

Degree or Major (specify): _____

Other training/education: _____

Employment:

Current Employer: _____

Position: _____



Respite Caregiver Profile, continued

Interests: (Check all that apply)

I am willing to care for children ages

birth - 2 _____ 2 - 5 _____ 5 - 8 _____ over 8 _____

I am willing to provide care (check all that apply):

_____ at my home	_____ weekdays
_____ at child's home	_____ weekends
_____ during the day	_____ overnight
_____ during evenings	_____ anytime

When I provide care, I will care for:

_____ only the child with disabilities
_____ the child with disabilities plus siblings
_____ the child with disabilities and other children in my care
_____ the child with disabilities and my own child/children

I would prefer to provide care:

_____ as a volunteer
_____ in exchange for a service (i.e., transportation, lawn care, meals, etc.)
_____ for an hourly rate of \$ _____
_____ for a negotiable hourly rate

How far are you willing to travel to provide care? (Check all that apply.)

_____ Williamsburg/James City County	_____ Hampton
_____ York County	_____ Poquoson
_____ Newport News	_____ Gloucester



Respite Caregiver Profile, continued

References:

Please provide the names, addresses, and phone numbers of two persons we may contact who have known you for more than 1 year (excluding relatives or roommates).

Name: _____ Phone: _____

Address: _____

Name: _____ Phone: _____

Address: _____

I am most interested in providing respite care because _____

Thank You!



Reference Check

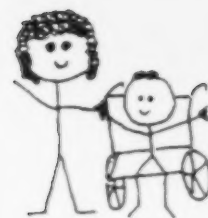
Date: _____

Name of Potential Caregiver: _____

Name of Reference: _____ Phone: _____

1. How do you know _____ ?
(put name of potential caregiver here.)
2. How long have you known _____ ?
3. What words best describe _____ ?
4. How would you best describe how _____
relates to children?
5. Describe what you think are _____'s strong
points in working with children with special needs and their families?
6. Are there any other comments about _____
you would like to make?





Final Activity

Step 1: Identify training goals.

What do you want your caregiver to learn about your child and family routines?

I want my caregiver to learn about these routines:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____



Step 2: List training methods.

What methods will you use to teach your caregivers?

In order to reach these goals I will use the following methods:

Goal 1: _____

Methods:

1. _____

2. _____

3. _____

Goal 2: _____

Methods:

1. _____

2. _____

3. _____



Goal 3: _____

Methods:

1. _____

2. _____

3. _____

Goal 4: _____

Methods:

1. _____

2. _____

3. _____

Goal 5: _____

Methods:

1. _____

2. _____

3. _____

Step 3:

Use resources to help train your caregiver.

What information will you use to help your caregiver learn?

These are the resources I would like to use:

- ☐ books
- ☐ handouts
- ☐ videotapes
- ☐ audiotapes
- ☐ computer search
- ☐ I develop resources
- ☐ other (please describe)



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I will know a specific skill or routine has been learned when we accomplish the following:

Goal 1: _____

Goal 2: _____

Goal 3: _____

Goal 4: _____

Goal 5: _____

